

**Report of the Secretary's Advisory Committee on Infant  
Mortality (SACIM):  
Recommendations for  
Department of Health and Human Services (HHS) Action  
and  
Framework for a National Strategy**

**Submitted  
January, 2013**

## *Executive Summary*

Infant mortality is a reflection of a society's commitment to ensuring access to health care, adequate nutrition, a healthy psychosocial and physical environment, and sufficient income to prevent the adverse consequences of poverty. While progress has been made in reducing U.S. infant mortality rates, the nation must do more. Inequality is shown in substantial and persistent racial/ethnic and income disparities. Moreover, in 2010, the U.S. ranked 24th in infant mortality compared to other industrialized nations of the world.

In June, 2012, Health and Human Services (HHS) Secretary Kathleen Sebelius made a commitment to the development of the nation's first national strategy to reduce infant mortality. This report of the Secretary's Advisory Committee on Infant Mortality (SACIM), as empaneled for 2011-2012, makes recommendations to serve as the framework for the Secretary, HHS agencies, and the entire federal government as they define and implement an official federal action plan. In addition, we stand prepared to assist further in development and dissemination of a public-private national strategy to reduce infant mortality.

First, the nation should set objectives that reflect our commitment. In 2010, the U.S. infant mortality rate was 6.15 deaths per 1,000 live births, and the average for industrialized countries was 5. The Healthy People 2020 objective is set at 6.0 per 1,000. Based on recent trends, however, SACIM believes the targets should be "five-five by fifteen" and "four-five by twenty" – that is, the United States should aim to reduce the infant mortality to 5.5 per 1000 by 2015, and to 4.5 by 2020.

Second, any plan or strategy to reduce infant mortality should be grounded in a set of core principles. The following core principles were defined by SACIM to guide the recommendations in this report. We believe that the national strategy and the HHS action plan to reduce infant mortality should:

- Reflect a life course perspective
- Engage and empower consumers
- Reduce inequity and disparities and ameliorate the negative effects of social determinants
- Advance systems coordination and service integration
- Protect the existing maternal and child health safety net programs
- Leverage change through multi-sector, public and private collaboration
- Define actionable strategies that emphasize prevention and are continually informed by evidence and measurement.

SACIM proposes six strategic directions or “big ideas”. These strategic directions define key areas for action and each incorporates specific SACIM recommended strategies and activities. Note that the Affordable Care Act (ACA) provides opportunities within each area. In addition, many actions recommended by SACIM require a change in approach rather than new investment or budget. The six big ideas/strategic directions call for the nation to:

1. **Strategic Direction 1: Improve the health of women before during, and beyond pregnancy.** Nothing could be more critical to the health of the next generation than to improve the health of women prior to conception. The nation is on the right track with ACA, including: affordable coverage, emphasis on clinical preventive services, innovations to better serve those covered by Medicaid, interventions for chronic conditions and mental health, and community public health and preventive services investments. Women need clinical services, community services, and social supports to empower them to achieve optimal health and fulfill their reproductive health goals. Effective implementation of such efforts will result in improved birth outcomes, optimal health for infants, and reduced infant morbidity and mortality.

Recommendations:

- 1.A. Monitor coverage and promote use of women’s clinical preventive services.
- 1.B. Partner with professionals to develop clinical guidelines for well-woman visits.
- 1.C. Use Medicaid innovation, demonstrations, and flexibility to offer states new avenues for delivering effective, evidence-based interventions to women.
- 1.D. Increase efforts to ensure mental/behavioral health and social support services for women.

2. **Strategic Direction 2: Ensure access to a continuum of safe and high-quality, patient-centered care.** Currently, the Collaborative Innovation and Improvement Networks (COIIN) supported by the Health Resources and Services Administration, Medicaid perinatal quality improvement projects, and action in select hospitals and health systems demonstrate what can and should be done. The Agency of Healthcare Research and Quality and other entities have defined measures. Still, we have far to go toward assuring that all women and infants receive quality care as defined by the Institute of Medicine, that is, care which is safe, timely, effective, efficient, equitable, and patient- centered.

Recommendations:

2.A. Strengthen state leadership and capacity to improve birth outcomes and reduce infant mortality through the HRSA Collaborative Innovation and Improvement Network (COIIN).

2.B. Use Medicaid to drive quality and improve the health of women and infants.

2.C. Support quality improvement activities through other agencies of HHS, including the Agency for Healthcare Research and Quality (AHRQ) and CDC.

2.D. Support health coverage for all newborns by requiring newborn coverage for all infants (i.e., with public or private coverage) and making temporary coverage available to those who are uninsured at birth.

2.E. Maximize the ACA investments in community health centers and workforce capacity.

3. **Strategic Direction 3: Redeploy key evidence-based, highly effective preventive interventions to a new generation of families.** We know that breastfeeding, family planning, immunization, smoking cessation, and safe sleep are proven, effective interventions for reducing infant mortality. It is clear, however, that new, culturally congruent social marketing messages and modern communication strategies (i.e., social networking, Internet) are essential to inform and motivate today's young families. Support and adequate financing for these proven prevention strategies is equally critical.

Recommendations:

3.A. Design and implement new health promotion and social marketing campaigns to accelerate use of five key preventive interventions.

3.B. Conduct health promotion and social marketing campaigns to inform families about the warning signs of pregnancy complications and infant risks and the actions families should take when problems arise

4. **Strategic Direction 4: Increase health equity and reduce disparities by targeting social determinants of health through both investments in high-risk, under-resourced communities and major initiatives to address poverty.** The underlying causes of persistent racial/ethnic and socioeconomic disparities in infant mortality must be specifically tackled. Poverty and racism profoundly affect psychosocial well-being and are widely considered to be contributors to disparities in birth outcomes and infant mortality. A national strategy to reduce infant mortality must include sustained commitment to address social determinants of health in order to increase health equity.

SACIM recommends comprehensive, community-based initiatives that increase access, opportunity, and resources in high-risk areas. SACIM also strongly recommends concerted efforts to reduce the impact of poverty on families in their childbearing years.

Recommendations:

- 4.A. Convene an interagency expert panel to set goals for closing infant mortality gaps.
  - 4.B. Support and transform the federal Healthy Start program and maximize its potential to reduce infant mortality, eliminate disparities, and increase health equity.
  - 4.C. Use federal interagency collaboration to turn the curve on social determinants of health at the community level by concentrating investments from multiple programs in place-based initiatives.
  - 4.D. Address and alleviate poverty, which has a known impact on infant mortality, through enhanced use of income supports through TANF, EITC, and other policies.
  - 4.E. Add SACIM to list of HHS Initiatives aiming to eliminate disparities and increase health equity.
5. **Strategic Direction 5: Invest in adequate data, monitoring, and surveillance systems to measure access, quality, and outcomes.** The nation's vital statistics system, perinatal surveys, Medicaid perinatal data collection, quality measurement systems, and other data systems need to be dramatically improved. Timely and accurate data are needed to help inform the development and implementation of important policies and programs for families across the country.

Recommendations:

- 5.A. Make investments in the National Vital Statistics system to assure timely, and accurate birth and maternal and infant death statistics.
- 5.B. Incentivize reporting of Medicaid perinatal data from every state, based on a uniform set of quality and outcome measures.
- 5.C. Provide resources to expand the Pregnancy Risk Assessment and Monitoring System (PRAMS) to every state in order to monitor the health of women and infants.
- 5.D. Systematic use of quality measures for women and children.
- 5. E. Continue support for other related data systems.
- 5.F. Give priority to research into the causes and prevention of infant mortality through NIH, AHRQ, HRSA, CDC, CMS, SAMHSA, and other parts of HHS

6. **Strategic Direction 6: Maximize the potential of interagency, public-private, and multi-disciplinary collaboration.** It is time for all sectors beyond public health and medicine to embrace infant mortality as "their" issue and strategically maximize their investments. For example both the HHS Action Plan to Reduce Racial and Ethnic Health Disparities and the National Prevention Strategy contain activities designed to improve reproductive health and birth outcomes. SACIM believes that actions are needed at the national, state, community, family, and individual levels, and through public-private partnerships to leverage innovation, technology, expertise, and community assets to achieve the goal of eliminating preventable infant deaths.

Recommendations:

- 6.A. Engage the National Prevention Council and build upon the National Prevention Strategy.
- 6.B. Strengthen state health departments with effective federal-state partnerships, particularly through activities underway at HRSA, CMS, and CDC.
- 6.C. Maximize the potential of public-private partnerships, particularly by engaging private sector organizations which have a distinct focus on preventing infant mortality.
- 6.D. Engage women (daughters, mothers, and grandmothers) in efforts to prevent infant mortality, improve women's health, and strengthen family health and well-being.

These SACIM recommendations acknowledge that reducing infant mortality in the United States will require a multi-faceted effort, including practice improvement by service providers, changes in knowledge, attitudes and behaviors of men and women of childbearing age, improved access to preventive and treatment services, empowered communities, health equity, and a serious commitment to prevention by all.

SACIM believes in the vision of the United Nations "Every Woman, Every Child" campaign: each nation should aim to ensure that every woman and every child have the same opportunities for health and life. We know that the first years of life lay the foundation for an individual to be healthy and thrive across the life course. Families, communities, states, and the federal government must work together to optimize the potential of every child. A nation as wealthy as ours can and should commit to ensuring medical, economic, and social support to families sufficient to allow every baby to be born in optimal health and to enter the world wanted and loved. Anything less would fail to achieve significant and lasting improvement.

# **Report of the Secretary's Advisory Committee on Infant Mortality: Recommendations for HHS Action and Framework for a National Strategy**

## ***I. Background on the Problem of Infant Mortality***

### **Understanding Infant Mortality in the United States**

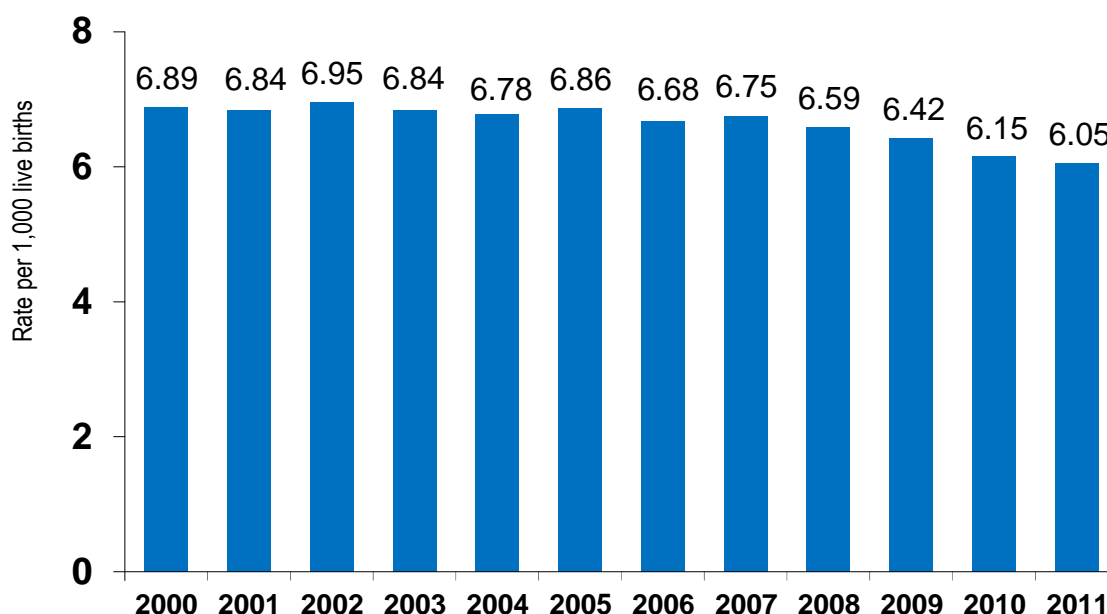
Infant mortality, deaths to infants during the first year of life (measured as the rate of infant deaths per 1000 live births), has long been understood to be a reflection of how well a society takes care of its most vulnerable citizens. Infant mortality is a multi-factorial phenomenon, with rates reflecting a society's commitment to the provision of: high quality health care, adequate food and good nutrition, safe and stable housing, a healthy psychosocial and physical environment, and sufficient income to prevent impoverishment. As such, our ability to prevent infant deaths and to address long-standing disparities in infant mortality rates between population groups is a barometer of our society's commitment to the health and well-being of all women, children and families.

Because of its multifactorial nature, risk factors for infant mortality include those related to women's health prior to and during pregnancy, those related to the pregnancy experience, those associated with the birth and newborn experience, and those associated with the child's health and well-being in the first year of life. Thus, many points of intervention for reducing infant mortality exist, and approaches are as disparate as expanding access to: primary care or family planning prior to pregnancy, high-quality prenatal care, specialty treatments for preterm or sick infants, breastfeeding support and immunizations, and safe housing and healthy neighborhoods.

#### ***Infant Mortality Rates and Trends***

The U.S. infant mortality rate has been declining over the past several decades, with some years of stagnation. In 2010, the reported rate was 6.15 deaths per 1,000 live births, and the provisional rate for 2011 was 6.05 per 1,000. (See Figure 1.) The decline is a significant achievement, driven by factors such as wide availability of life saving neonatal care, increases in access to primary care, and better nutrition. At the same time, racial-ethnic disparities in infant mortality remain, and preventable infant deaths continue to occur. Moreover, our international ranking points to opportunities for further progress.

**Figure 1. Infant Mortality Rate, U.S., 2000-2011**



**Source:** CDC/NCHS. National Vital Statistics System. 2011 data are provisional. Prepared for SACIM by MacDorman, November, 2012.

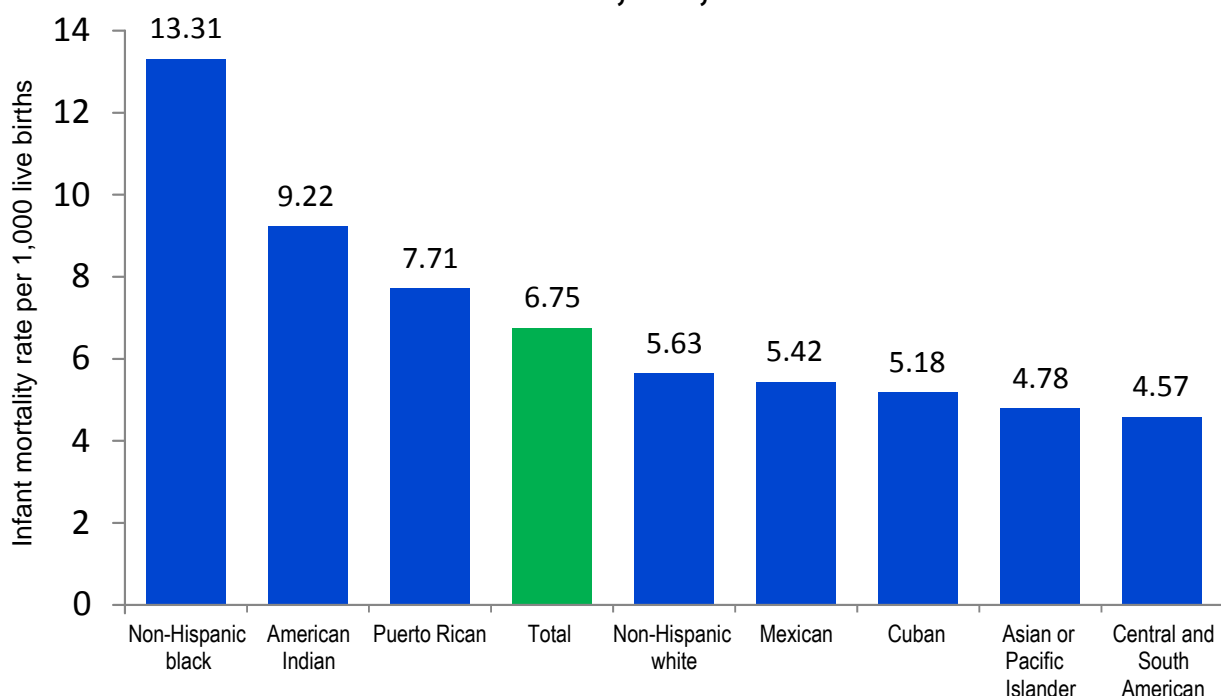
Racial/ethnic disparities in infant mortality have persisted over the last several decades and are a major reason infant mortality remains a focal public health issue. Of special concern are the very high rates of infant death among Non-Hispanic Black women (African-American), American Indian or Alaska Native, and Puerto Rican mothers. In particular, the risk of infant death for babies born to non-Hispanic black women has consistently been more than two times greater than the risk of infant death for non-Hispanic white women for decades; in 2007 and 2008, the infant mortality rate for non-Hispanic black women was 2.4 times the rate for non-Hispanic white women.<sup>1 2</sup> (See Figure 2.) Studies of the racial/ethnic disparities in fetal, infant and maternal mortality suggest that not all race/ethnic groups have benefited equally from social and medical advances.

Preterm birth (prior to 37 weeks gestation) is a factor driving disparities in infant mortality. Higher infant mortality rates for non-Hispanic black women and Puerto Rican women in the United States compared to non-Hispanic white women are largely due to higher rates of preterm birth and preterm related causes of death in these populations.<sup>3</sup> Preterm related causes of death



account for half of the gap between non-Hispanic black and non-Hispanic white infant mortality rates. In 2007, 78% of the higher rates of infant mortality for Non-Hispanic black women compared to Non-Hispanic white women was attributed to higher rates of preterm births among non-Hispanic blacks; for Puerto Rican women 100% of their higher rates of infant mortality compared to non-Hispanic whites was accounted for by higher rates of preterm birth. In contrast, among American Indian/Alaska Natives, 76% of their higher infant mortality rates in 2007 were due to higher infant death rates at each gestation of 34 weeks or more. For American Indians/Alaska Natives, high rates of unintentional injuries and deaths from Sudden Infant Death Syndrome (SIDS) play a major role in infant mortality.<sup>4 5 6</sup>

**Figure 2. Infant Mortality Rates by Race-Ethnicity of Mother, US, 2007**



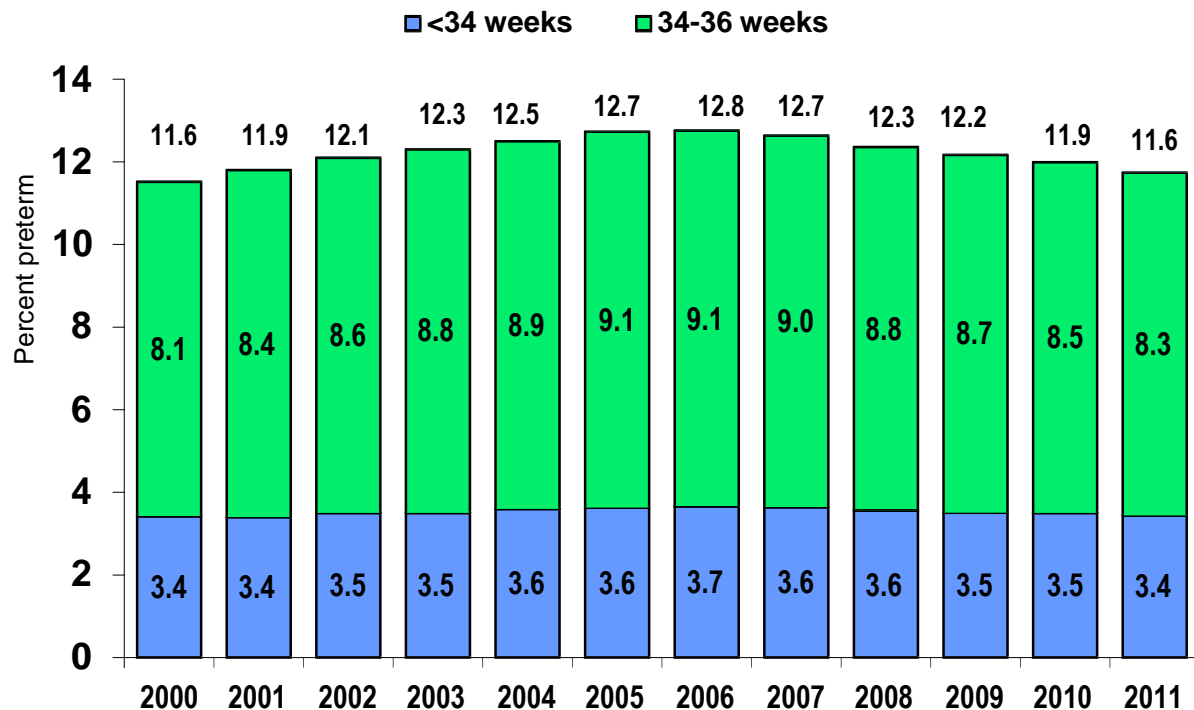
**Source:** MacDorman MF, Mathews TJ. Understanding Racial and Ethnic Disparities in U.S. Infant Mortality Rates. *NCHS Data Brief* no. 74. Hyattsville, MD: US Department of Health and Human Services, CDC, National Center for Health Statistics; 2011. Available at <http://www.cdc.gov/nchs/data/databriefs/db74.htm>.

Preterm birth is a major contributing factor to the overall U.S. infant mortality problem, as well as to childhood morbidity and disabilities. (See Figure 3.) The infant mortality rate per 1,000 live births for infants born at less than 32 weeks of gestation was nearly 70 times the rate for infants born at between 37 and 41 weeks of gestation.<sup>7</sup> Children who survive have a higher risk of morbidity, including: neuro-developmental disabilities ranging from major disorders such as cerebral palsy and mental retardation to more subtle disorders such as language and learning problems, attention deficit hyperactivity disorder, and social-emotional difficulties. Preterm infants are also at increased risk for special health care needs related to health problems such as asthma.<sup>8</sup>

With preterm birth a major contributor to infant mortality in general, in particular to disparities in the United States, much of the success our nation has achieved in reducing infant mortality rates has been in keeping small infants alive rather than preventing their birth. Importantly, this approach to infant death reduction has come at great costs to our families, to our medical system, to taxpayers, and to society in general. The Institute of Medicine (IOM) estimated that in 2005 the average direct cost of medical care for a preterm infant in the United States was more than \$30,000, with the majority (85%) of this cost being incurred during the first year of life. The average cost per infant increased to \$51,600 when the costs of maternal medical care, early intervention and special education services, and lost household productivity were considered. The annual societal economic burden associated with preterm birth in the United States was in excess of \$26 billion in 2005.<sup>9</sup> These costs grow each year with medical care inflation. Moreover, these estimates do not take into account the emotional toll on families who lose a baby or whose infant has adverse consequences.

The risk factors for preterm birth (and the somewhat overlapping category of low birthweight) are not fully understood.<sup>10</sup> In general, however, risk factors for preterm birth and low birthweight include: maternal cigarette smoking, high altitude, poor nutritional status, low pre-pregnancy weight, low pregnancy weight gain, low or high parity, maternal low birthweight, obstetric history, mode of delivery (i.e., elective cesarean section), use of drugs or alcohol, maternal morbidity (e.g., chronic hypertension, incompetent cervix), maternal age (< 17; >34 years), multiple gestation pregnancies, infection prior to and during pregnancy, short (< 18 mos.) and long interpregnancy interval (> 60 months), stress (individual and environmental), poor social support, adverse neighborhood environment (physical and social) and poverty. Notably, neighborhood conditions are independently and significantly associated with a risk of low birth weight. Lack of access to quality medical care prior to and during pregnancy is also sometimes understood to be a risk factor for preterm delivery, but barriers in access to care might equally be viewed as a precursor to the multiple health risk factors delineated above.

**Figure 3. Percentage of Births that were Preterm, United States, 2000-2011**



Source: CDC/NCHS, National natality data files. 1984-2010 are final birth data, 2011 data are preliminary. Prepared for SACIM by MacDorman, November, 2012.

This long list of risk factors for preterm birth/low birthweight clearly points to strategies which may improve pregnancy outcomes. Some of these strategies have already been shown to make a difference but are not equitably and or universally implemented in the United States, while other strategies have not been thoroughly tested, may improve outcomes but not affect disparities, may have individual but not population impact, or require extensive resources within and beyond the medical care system and public health systems. As we consider strategies below, these considerations will be addressed. This listing of risk factors for preterm birth/low birthweight also points to some major themes with respect to intervention: the importance of action across generations and across the life course, the importance of women's health before, during and after pregnancy, the importance of community and environmental health, and the importance of psychosocial-economic factors in maternal and infant health and well-being.

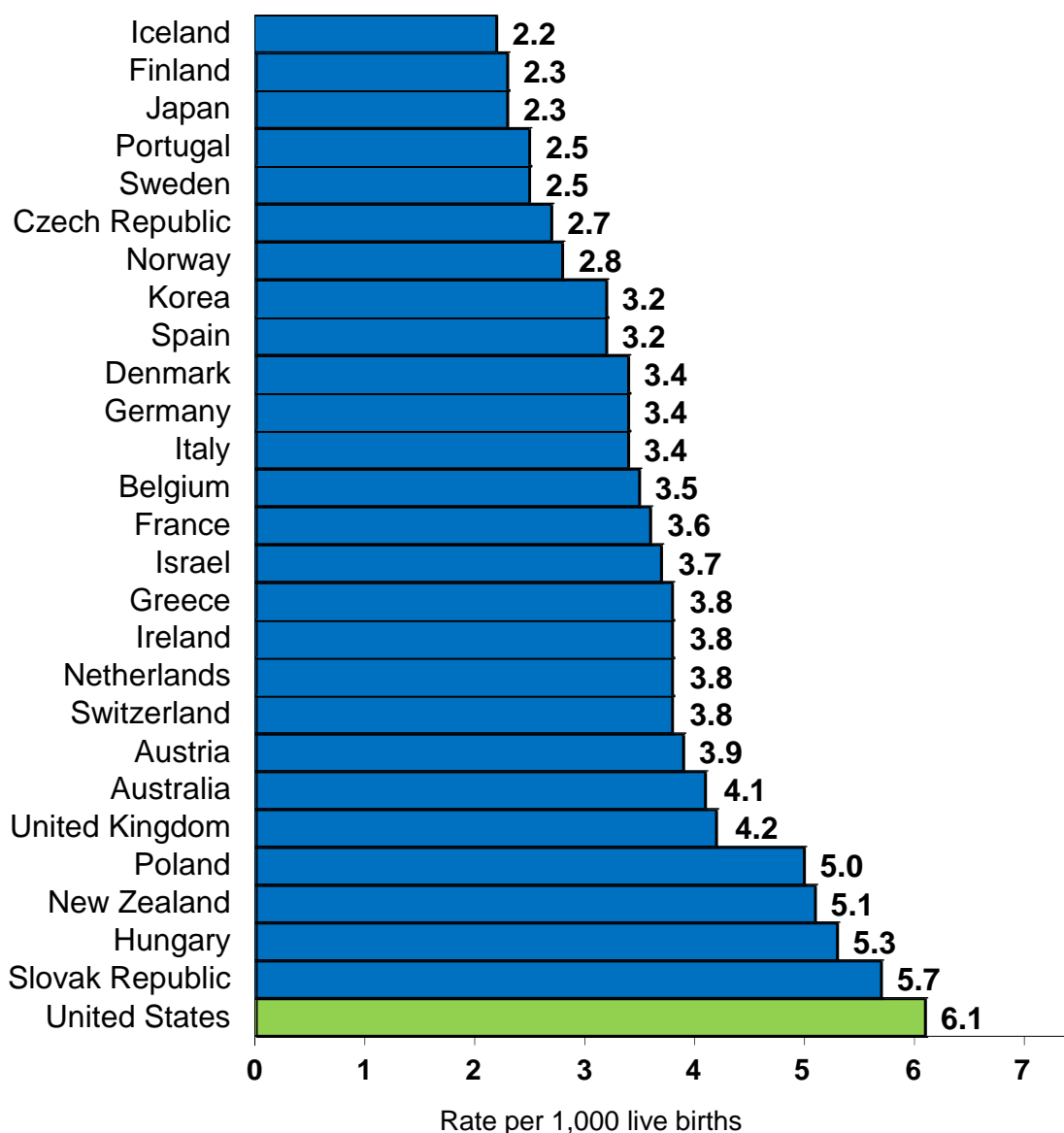
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*“Preterm birth is a complex cluster of problems with a set of overlapping factors of influence. Its causes may include individual-level behavioral and psychosocial factors, neighborhood characteristics, environmental exposures, medical conditions, infertility treatment treatments, biological factors, and genetics. Many of these factors occur in combination, particularly in those who are socioeconomically disadvantaged or who are members of racial and ethnic minority groups.”* Institute of Medicine. *Preterm Birth*. 2006, page 2.

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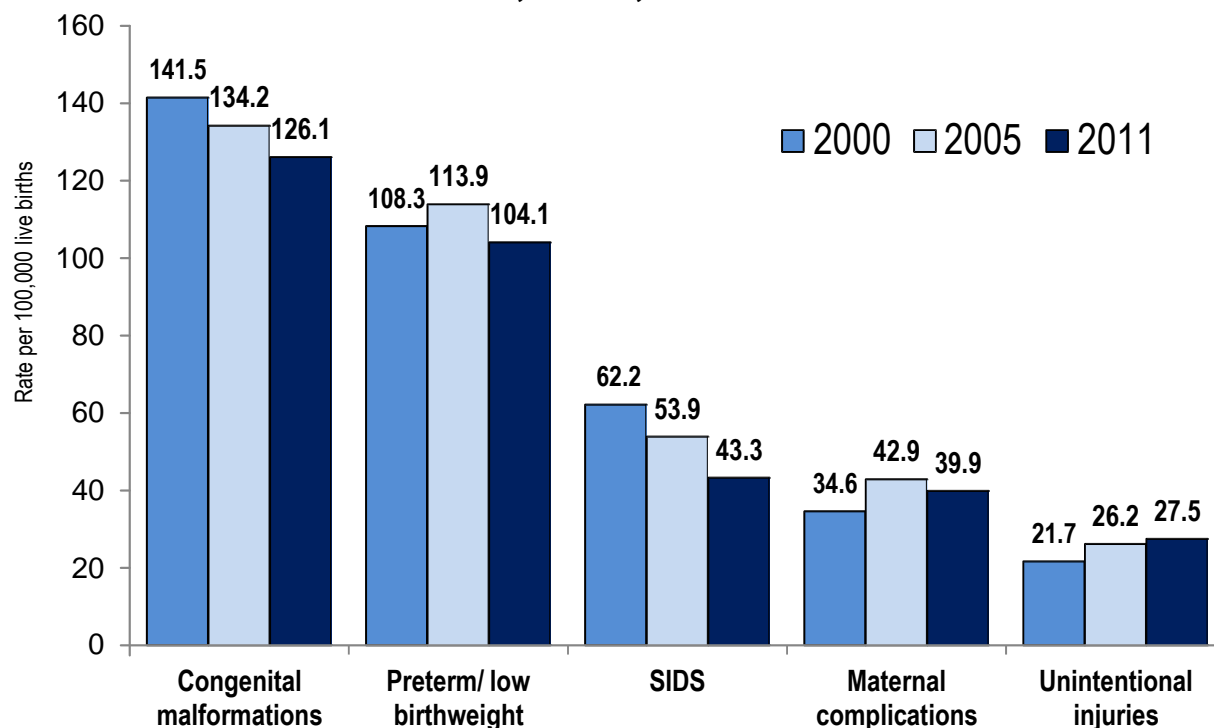
In 2010, the U.S. ranked 27th in infant mortality compared to other nations in the Organization for Economic Cooperation and Development (OECD). (See Figure 4.) The U.S. infant mortality rate is higher than the industrialized country average of 5 per 1,000 live births and is greater than the infant mortality rates in most of Western Europe, Canada, Israel, and Japan. Particularly worrisome is that the U.S. rank among nations in the OECD group has consistently dropped since 1960 when the United States ranked 12<sup>th</sup>. By 1980 the US ranked 19<sup>th</sup>, dropping to 30<sup>th</sup> in 2005 and then 27th in 2010. Differences in how live births are recorded in the OECD nations may affect some of the comparisons; however, researchers at the National Center for Health Statistics (NCHS), CDC, HHS do not report this to be a main cause of our low ranking. Better explanations for the differential in infant mortality rates between the United States and other OECD nations are differences across these nations in rates of preterm and low birthweight births and persistent racial/ethnic disparities in U.S. infant mortality.<sup>11</sup> The CDC estimated that if the United States had the same distribution of births by gestational age as Sweden, then 8,000 U.S. infant deaths would be averted each year and our nation’s infant mortality rate would be one-third lower than current rates.<sup>12</sup> Looking globally, the United States – along with Brazil, India, and Nigeria – is among the ten countries with the highest numbers of preterm births.<sup>13 14 15</sup>

**Figure 4. Infant Mortality Rates, OECD Countries, 2010**



Source: Source: Organization for Economic Cooperation and Development. Available at: [http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH\\_STAT](http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT) Accessed November 10, 2012.

**Figure 5. Infant Mortality Rates for the Five Leading Causes of Death, United States, 2000, 2005, and 2011**



Source: CDC/NCHS, Mortality Data. 2011 data are preliminary. Prepared by MacDorman for SACIM, November 2012.

Importantly, although we emphasize preterm birth, other major causes of death in the first year of life include congenital malformations, Sudden Infant Death Syndrome (SIDS, now expanded to include Sudden Unexpected Infant Death - SUID), maternal complications, and unintentional injuries. More than half of infant deaths are attributable to these five leading causes.<sup>16</sup> (See Figure 5.)

One in 33 infants is born with a congenital malformation (also known as birth defects), and one in five infant deaths is due to a congenital malformation. Rates of birth defects contribute to preterm and low birthweight birth rates and they share some risk factors.<sup>17 18</sup> Some birth defects can be prevented with ensuring adequate nutrition before and during pregnancy, (particularly folic acid supplementation prior to pregnancy), ensuring women with diabetes are in good glycemic control before and during pregnancy, maintaining or achieving a healthy pre-pregnancy

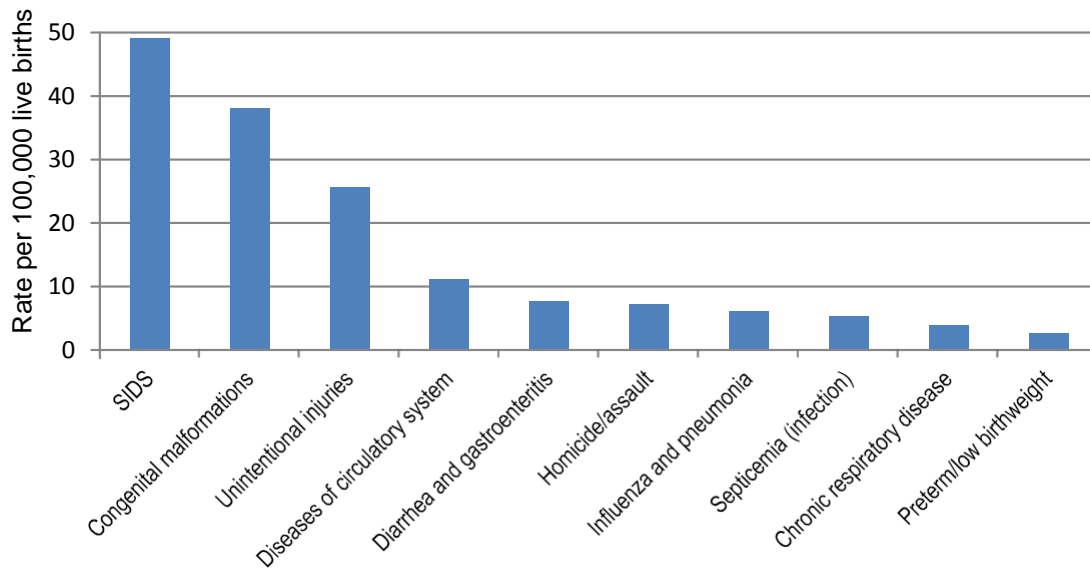
body mass index (healthy weight), ensuring adequate pregnancy intervals, and avoidance of alcohol, tobacco, and certain teratogenic drugs and medications.<sup>19 20 21 22</sup>

While most deaths resulting from preterm birth and congenital malformations occur in the neonatal period (deaths within the first 28 days of life), some other causes of infant mortality — particularly SIDS/SUID, injuries, diarrhea, homicide, septicemia, and influenza/pneumonia — are more likely to manifest in the postneonatal period (deaths between 28 days and one year). (See Figure 6.)

For some groups, including Native American and Alaskan Native infants, postneonatal mortality rates are particularly high.<sup>23</sup> Widening gaps in socio-economic conditions and health behaviors also may be a factor.<sup>24</sup> Thus, unequal treatment, social determinants of health, and inequities associated with postneonatal mortality also are a factor in the overall racial-ethnic disparities in infant mortality.

Of particular concern is that many of the leading causes of postneonatal mortality are considered preventable. Some effective interventions that make a difference in postneonatal mortality are well-known but not sufficiently and/or universally implemented in the United States at this time, including breastfeeding, immunizations, safe sleep (to prevent SIDS/SUID), family planning, immunizations, and WIC nutrition supplements. Having a pediatric medical home can support the efforts of families to protect their infant's health and development. Other interventions that also directly affect infant/child health and well-being independent of an infant's health status at birth are socioeconomic and psychosocial supports that allow parents to properly care and provide for their infants and children, included in key home visiting program models. Assuring the safety of infants is critical to their survival; no infant should die as a result of an accidental injury, preventable infection, child maltreatment, or homicide.

**Figure 6. Top Ten Leading Causes of Postneonatal Mortality, U.S., 2009**



Source: Heron M. Deaths: Leading Causes for 2009. National Vital Statistics Reports. 2012 Oct. 26; 61(7). Table 3. CDC/NCHS, Mortality Data. Available at: [http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61\\_07.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_07.pdf).

Over the past two years, SACIM has studied, listened, and learned about the causes, correlates, and trends for U.S. infant mortality. Given the facts and description of the problem here described we are making recommendations to the Secretary to guide development of an HHS action plan and a public-private national strategy to reduce infant mortality between now and 2015.



## ***II. Principles for a national strategy on infant mortality***

In June, 2012, Health and Human Services (HHS) Secretary Kathleen Sebelius made a commitment to the development of the nation's first national strategy to reduce infant mortality. This is a historic commitment and, consistent with its charter, the Secretary's Advisory Committee on Infant Mortality (SACIM) is prepared to assist with and guide the development of such a national strategy.

This SACIM report, based on the views of experts empaneled for 2011-2012, makes recommendations to serve as the framework for the Secretary, HHS agencies, and the entire federal government as they define and implement an official federal action plan. This is consistent with our charter, which calls for SACIM to report to the Secretary and to advise on HHS activities and programs that are directed at reducing infant mortality and improving the health status of pregnant women and infants.

In 2013, SACIM can assist in the development of a public-private national strategy to reduce infant mortality. Our charter also calls for SACIM to provide advice on how best to coordinate federal, state, and local government programs, as well as private sector resources and activities. SACIM is designed to represent "a public-private partnership at the highest level". Our membership includes 21 private sector experts from medicine (ob-gyn, pediatrics, family medicine), nursing, public health, epidemiology, consumer advocacy, health policy, and other fields. The ex-officio members represent 12 units of federal government including six health agencies, as well as the Departments of Education (DOE), Labor (DOL), Housing and Urban Development (HUD), Agriculture (USDA), and Administration for Children and Families (ACF)

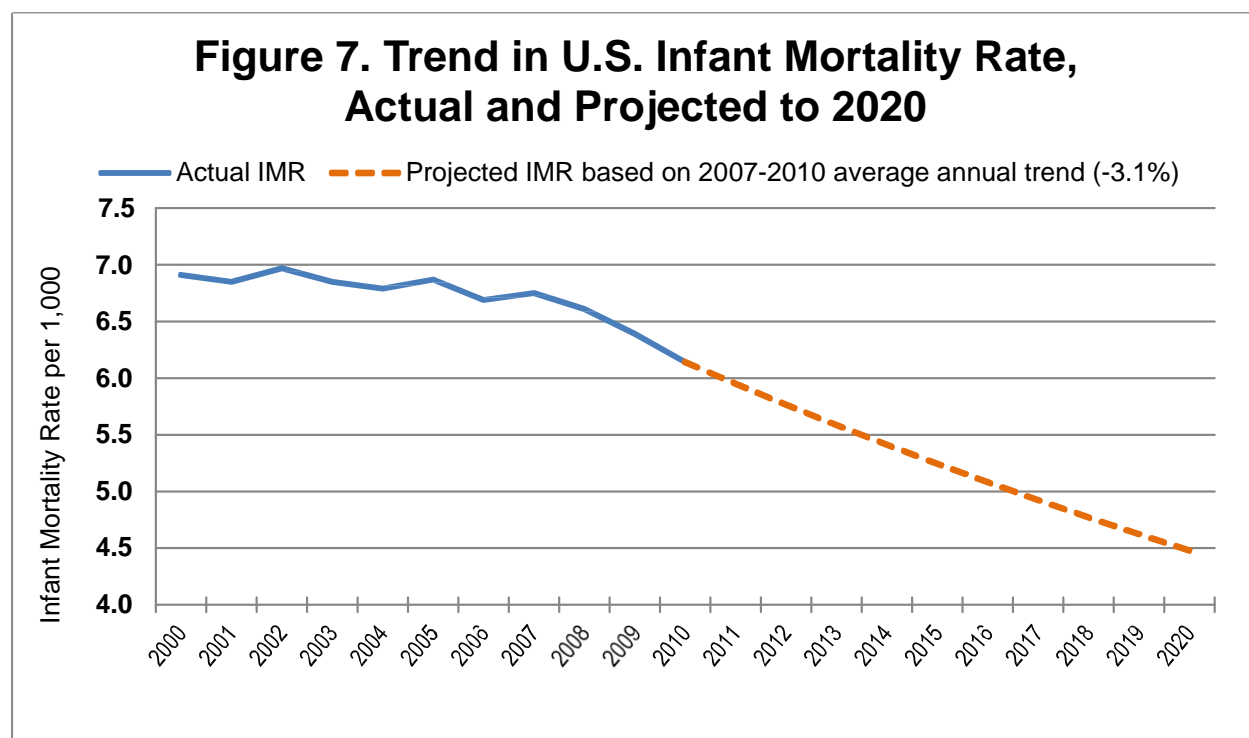
**SACIM recommends that we be designated as the entity that will facilitate development of a public-private national strategy to reduce infant mortality.** This national strategy would include both public and private sector strategies. This report focuses on recommendations for HHS action. It is intended to guide an HHS action plan and to serve as a framework for the national strategy to reduce infant mortality.

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“...in the U.S. we’ve seen our infant mortality rates steadily decline. This is thanks to cooperation between federal and local governments, community and faith organizations and the private sector. But today we still lose far too many children in the first years of their lives... where infant mortality has taken the highest toll in the US, we’re also partnering with state officials to create strategies and interventions to begin bringing these rates down. Our plan is to find out what works and scale up the best interventions to the national level.... I’m pleased to announce my department will be collaborating in the next year to create our nation’s first ever national strategy to address infant mortality.” HHS Secretary Kathleen Sebelius, June 14, 2012

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SACIM believes strongly that the nation should set objectives that reflect a strong commitment to reducing infant mortality. In 2010, the U.S. infant mortality rate was 6.15 deaths per 1,000 live births, and the average for industrialized countries was 5. The Healthy People 2020 objective is set at 6.0 per 1,000. Figure 7 shows how continued progress at an average annual decline of 3.1 percent could yield greater progress. **Based on recent trends, however, SACIM recommends that the targets should be “five-five by fifteen” and “four-five by twenty” – that is, the United States should aim to reduce the infant mortality to 5.5 per 1000 by 2015, and to 4.5 by 2020.**



Source: Maternal and Child Health Bureau, HRSA. Presented by Lu to SACIM, July, 2012.

We know that reducing infant mortality will require a multi-faceted, comprehensive national strategy. We also know that simply making better use of effective services and programs will make a difference. Archimedes, in asserting the principle of leverage, is quoted as saying: “Give me a lever long enough and a fulcrum on which to place it, and I shall move the world.” We have the lever of resolve to eliminate infant mortality. We need to use the fulcrum made up of existing policies, programs, and practices in order to move the world. Effectively and efficiently leveraging existing resources and knowledge will be the primary route to further reducing the infant mortality rate of our nation.

It is also clear that we cannot close the infant mortality gap with medical care alone. More population-based public health and prevention efforts and greater investments in health equity will be needed. Both the National Prevention Plan and the work of the Surgeon General’s Prevention Council include key strategies to improve the health of women, infants, families, and communities. Many of strategies discussed in this SACIM report can also be found in the National Prevention Strategy and the HHS Action Plan to Reduce Racial and Ethnic Health Disparities; many others are based on provisions of the Affordable Care Act.

Any plan or strategy to reduce infant mortality should be grounded in a set of core principles. The following core principles were defined by SACIM to guide the recommendations in this report. We believe that to be effective, a multi-faceted strategy to reduce infant mortality should:

- Reflect a life course perspective
- Engage and empower consumers
- Reduce inequity and disparities and ameliorate the negative effects of key social determinants
- Advance system coordination and service integration
- Protect the existing maternal and child health safety net programs
- Leverage change through multi-sector, public and private collaboration
- Define actionable strategies that emphasize prevention and are continually informed by evidence and measurement.

***Reflecting a life course perspective.*** While all of the factors driving adverse birth outcomes and infant mortality are not understood, the Institute of Medicine and other experts have identified risks that can be addressed now, with current knowledge.<sup>25</sup> Success will require a continuum of services starting before pregnancy, continuing with appropriate and high-quality prenatal and birth services, and addressing the needs of women and infants after the birth. (See figures in Appendices A and B which show the major service components needed in this continuum.)

Over the past fifty years, progress in reducing infant mortality has largely been the result of saving babies born too soon or too small. The success of regionalization of neonatal care and perinatal services was instrumental in the major declines in infant mortality since the 1970s. In fact, greater adherence to the successful practices of regionalized perinatal care could contribute to lower infant and maternal morbidity and mortality.<sup>26</sup> Building more prevention efforts onto our nation's outstanding capacity to save preterm and low birthweight babies is the next frontier.

For decades, prenatal care has been a primary national strategy for reducing infant mortality. Prenatal care offers the opportunity to identify maternal risk factors, particularly those that emerge during pregnancy. Prenatal visits are a process, through which evidence-based and informed practices can be matched to a woman's health and pregnancy conditions. Interventions to promote smoking cessation, identification of gestational diabetes, linkage to needed social services or specialty care, and education on healthy weight and nutrition are just a few of the advantages conferred by prenatal care. Providing prenatal care that begins early, continues throughout pregnancy, and is tailored to needs is recommended.<sup>27 28 29 30</sup> Inadequate amounts of care, not even accounting for the quality of care, has been associated with increased risk of prematurity, stillbirth, and infant death.<sup>31</sup>

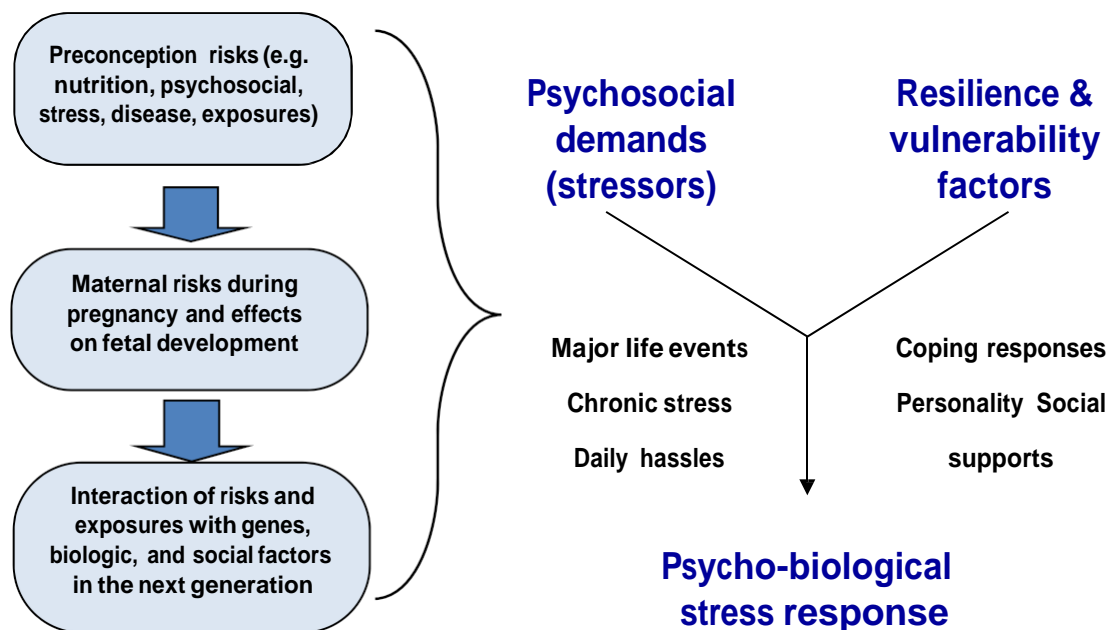
Prenatal care is important; yet for many families, prenatal care comes too late to reduce risks, complications, or deaths among mothers and babies.<sup>32 33 34</sup> And, most birth defects occur in the first few weeks of pregnancy, typically before the first prenatal visit and thus too late for key birth defects prevention opportunities. Experts now recognize that to improve birth outcomes, we must first improve women's health before pregnancy, prior to conception. National recommendations call for promotion of preconception health and health care to further reduce infant mortality.<sup>35</sup> Effective, evidence-based services have been identified.<sup>36 37</sup> In 2008, prior to the ACA health reforms, policy experts recommended: 1) coverage for adult women, 2) preventive services, including family planning and preconception care, without cost sharing; 3) patient protections (e.g. confidentiality and guaranteed issue); and 4) interconception care to women with a prior adverse pregnancy outcome in Medicaid.<sup>38</sup> Since 2005, the CDC, in partnership with a coalition of public and private partners, has led a national movement to improve preconception health and health care.<sup>39</sup> The Office of Minority Health also has launched a campaign to promote women's preconception health through peer education in communities of color.

The life course perspective is a way of looking at life not as disconnected stages, but as an integrated continuum of events and interactions.<sup>40</sup> New science has led to increasing recognition of how the health of a woman before conception can affect the outcome of pregnancy, and that the health and development of an infant can affect well-being throughout a lifetime. There is growing scientific understanding of the interactions among biologic, genetic, psychosocial, and environmental factors and their effect on pregnancy outcomes and lifelong health.<sup>41 42</sup> (See

Figure 7.) In addition, research suggests that many chronic childhood diseases such as asthma, autism, and obesity, as well as chronic adult diseases such as heart disease, diabetes, and cancer are influenced by what happens at the start of life from conception through the early childhood years.<sup>43 44 45</sup>

SACIM recognizes the importance of using a life course perspective to understand health and human development, particularly in the case of women and infants. Science tells us that a lifetime of optimal health and human development begins in the “first 1,000 days” from the prenatal period through the first two years.

**Figure 7. Interactive Impact of Risk, Stress, and Resilience on Women and Infants**



Sources: Barker 1997; Steptoe 1998; McEwan 1998; Hemingway & Marmot 1999; Brunner & Marmot 1999; Wadsworth 1999; Halfon & Lu 2003; Misra et al 2003.

**Engaging and empowering consumers.** SACIM believes that the national strategy to reduce infant mortality should use a patient-centered approach and engage, empower, and activate mothers, families, and the broader community in the prevention of infant mortality. Evidence suggests that better outcomes will be the result.

Patient centeredness has become widely recognized as a key component of high quality health care. The Institute of Medicine (IOM) report on *Crossing the Quality Chasm* defined patient-centered care as “respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.”<sup>46</sup> To this end, achieving patient-centered care calls for action with, and not just for, the mother, family and community.

Mothers generally have important influence on the health and health care decisions of families. This includes decisions about pregnancy, nutrition, family safety, and when to seek health care. Fathers also have an important role to play in childbearing and influence child and family health outcomes and well-being. Engaging and informing parents is essential to improving the health and survival of infants. For example, parents must be effectively informed about and act on their knowledge about prevention strategies that can reduce the incidence of SIDS, injuries, and vaccine-preventable diseases. Professionals must understand parents perspectives and barriers to effective implementation of prevention strategies.

SACIM believes that mobilizing and harnessing the “experiential wisdom” of mothers, families and broader community across the entire spectrum of patient engagement — from empowering, informing and activating mothers, to partnering in the design of innovative care models and initiatives — will result in greater relevance, enhanced service utilization, and ultimately better outcomes for mothers, infants, and families.

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“It is time to refocus, reinforce, and repeat the message that health disparities exist and that health equity benefits everyone.” HHS Secretary Kathleen Sebelius, *HHS Action Plan to Reduce Racial and Ethnic Health Disparities*, page. 1

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***Reducing inequity, health disparities and the negative effects social determinants.*** It has been said that the definition of insanity is doing the same thing in the same way and expecting a different result. When W.E.B. Dubois pointed out that the health of the black population in the U.S. was worse than that of the white population in 1899, he would no doubt have expected that by now we would have made the moral commitment, defined the resources, and demonstrated the political will to eliminate the racial gap in adverse birth outcomes, infant mortality, and maternal mortality. In 2012, however, the two-to-three-fold racial gap in these adverse outcomes is as real today as it has been over the past decades. Addressing the racial and economic inequity, unequal treatment, and social determinants that drive disparities in infant and maternal

mortality, as well as birth outcomes overall, must be a priority in any national plan to reduce infant mortality.

*Advancing system coordination and service integration.* Currently, services for families are a patchwork at best, pieced together by communities and families from a set of discrete federal/state funding streams and categorical programs. A family that needs an array of services (e.g., Medicaid coverage, medical care, mental health treatment to combat maternal postpartum depression, family planning, early intervention services to assure optimal infant development, and nutrition supplements from WIC) often has to apply for eligibility under different programs, and identify and visit several provider sites. Many families fall through the cracks where there are large system gaps. Well-coordinated and integrated service systems are the exception rather than the norm in large and small, urban and rural communities across the country.

The Institute of Medicine has called for greater integration of public health and primary care in particular.<sup>47</sup> Whereas public health is designed to fulfill “society’s interest in assuring the conditions in which people can be healthy”<sup>48</sup> and primary health care has a similar goal, they can and should be mutually supportive and integrated components of a health system designed to improve the health of populations.

This work will require leadership and partnerships. Partnerships between federal, state, and local agencies, private providers and safety net clinics, and communities are needed. Within HHS, the Health Resources and Services Administration (HRSA) and Centers for Disease Control and Prevention (CDC) have missions focused on improving health and have particularly important roles to play in advancing system coordination and service integration. Specifically, the HRSA Maternal and Child Health Bureau (MCHB) is the only agency whose mission includes improving the health of all women, infants, children, and their families, including fathers. Partnerships are a key strategy within the mission of MCHB. The Institute of Medicine also has emphasized the importance of community engagement in defining and addressing population health.

In addition, innovative health care delivery strategies such as the medical home, accountable care organizations, and community health teams are underway in some areas of the country, but they are not widespread or close to universally available. Home visiting programs are serving as a means to connect families to services but only a small fraction of those families in need and at-risk are being served. SACIM believes that the national strategy to reduce infant mortality should make use of these and other approaches and incentives to increase system coordination and service integration.



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“What we need is more integration – vertical, horizontal, and longitudinal. Vertical integration in terms of appropriate levels of care; horizontal integration in terms of service coordination not only within healthcare but across systems – schools, social services, child welfare, and community programs; and longitudinal integration in terms of continuum of care across the life course.” Michael Lu, M.D., Associate Administrator for Maternal and Child Health, HRSA, SACIM Meeting, July 10, 2012.

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*Protecting key federal investments that make up the “maternal and child health safety net,”* including programs such as the Medicaid program, Title V Maternal and Child Health Services (MCH) Block Grant; Title X Family Planning; Community Health Centers; Healthy Start; Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program; and WIC Supplemental Nutrition Program. SACIM believes that cuts in these programs would be detrimental to any national strategy to reduce infant mortality.

- Prior to enactment of the ACA an estimated 40-50% of U.S. births were financed by **Medicaid**. With implementation of ACA, Medicaid will become an even more important source of coverage, especially for women of childbearing age. Since the mid-1980s, Medicaid coverage expansions have increased access to care for pregnant women and infants. Today, at the federal and state levels, Medicaid is leading efforts to improve the quality of a continuum of services including prenatal care, birth, newborn care, postpartum visits, interconception care, and well-baby visits. Yet variations in coverage and benefits have impeded access and quality.
- The **Title V MCH Block Grant** has been at the heart of our nation’s infant mortality reduction efforts for more than 75 years. Using approximately \$500 million in federal funds, states leverage more than \$6 billion to support the essential infrastructure at the national, state, and local level for the delivery of MCH services such as immunizations. Since its inception, Title V has served as the incubator for innovation in MCH services, seeding new approaches and programs and then working with public and private partners to ensure widespread and effective implementation. The creation of regional perinatal systems of neonatal intensive care units (NICUs), newborn screening programs, and systems of care for children with special health care needs are prime examples.
- The **Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program**, created through the ACA, makes grants to states to deliver evidence-based interventions to high-risk pregnant women, new mothers, infants, and young children in home and



community settings. Several of the HHS-approved MIECHV program models have demonstrated success in improving birth outcomes and reducing infant mortality (among other outcomes), and these models are being replicated in high-need communities across the country.

- The **Title X Family Planning program** assures access to family planning education and services for millions of women, particularly low-income and young women. Sixty percent of the women using Title X clinics consider these clinics their usual source of care. Each year, Title X prevents 973,000 unintended pregnancies. This is important because unintended pregnancies are highly correlated with adverse pregnancy outcomes including low birthweight, preterm birth, and infant mortality.
- **Community Health Centers** (CHCs, also known as Federally Qualified Health Centers – FQHCs – under Medicaid and Medicare) provide services to more than 20 million patients each year in medically underserved areas. CHCs provide the care associated with more than 17% of the births to low-income families. CHCs provide comprehensive primary care, including family planning, prenatal care, and infant care in communities that are otherwise medically underserved. Data show that where CHCs serve more low-income individuals in a state, the state’s African-American/white and Hispanic/white health disparities decline in such key areas as prenatal care and infant mortality rates.
- While HHS does not oversee **the Supplemental Nutrition Program for Women, Infants & Children (WIC) program**, the collaborative relationship between HHS and USDA to support the program is important, and in communities, WIC is closely integrated with other maternal and child health services. Each year, WIC reaches more than 2 million pregnant and postpartum women plus 2 million infants and nearly 5 million young children with nutrition counseling and food. Studies have shown that WIC is associated with reduced rates of low birthweight, a major precursor of infant mortality

**Leveraging through interagency, public-private, and multi-disciplinary collaboration and partnerships.** The American tradition is to achieve greatness through public-private collaboration and partnerships. Current efforts to reduce infant mortality have been stimulated by the ideas and action of non-profit organizations, state and local health departments, health professional associations, community-based organizations, academic institutions, and federal government agencies. Indeed, the composition of SACIM reflects this array of stakeholders. In terms of federal leadership, no one agency has the means and authority to undertake all that is recommended in this report. We strongly believe that the national strategy to reduce infant mortality must leverage public and private resources, promote further collaboration, and stimulate synergy.

**Defining actionable strategies that emphasize prevention and are continually informed by evidence and measurement.** The SACIM recommendations to guide the Secretary and HHS in development of the national public-private strategy and an HHS official action plan to reduce infant mortality focus on action, effective practices, and opportunities for both short- and long-term success. Too many reports and plans are more focused on describing the problem or setting out principles than on actionable strategies. This report focuses on actions we believe can be adopted in the next 3-5 years by HHS in partnership with other federal agencies, state and local governments, and private sector organizations and leaders.

### ***III. Strategic Directions for Reducing Infant Mortality: Six Big Ideas***

SACIM proposes six strategic directions or “big ideas”. These strategic directions define key areas for action and each incorporates specific SACIM recommended strategies and activities. We believe that HHS should take action in each of these six strategic directions and have made specific recommendations for each. Note that the Affordable Care Act (ACA) provides opportunities within each area. In addition, many actions recommended by SACIM require a change in approach rather than new investment or increased budgetary commitments.

#### **Strategic Direction 1. Improve the Health of Women Before, During, and Beyond Pregnancy**

The Obama Administration has given unprecedented attention to improving the health of women and girls through a variety of policies and initiatives. Continued emphasis is needed, particularly attention to the implementation of key policies and programs.

SACIM strongly believes that the Patient Protection and Affordable Care Act (ACA) offers major opportunities to further reduce infant mortality in the United States. This is particularly true in terms of improving the health of women. (A summary of SACIM list of opportunities to use the ACA for purposes of reducing infant mortality can be found in Appendix C.)

An estimated one in five women of childbearing age (15-44 years) was uninsured in 2008-09 and others were underinsured, without coverage for needed services. Women at highest risk for being uninsured include those who are: low income, young, single, and without high school completion. Women who are neither pregnant nor raising children are particularly likely to be uninsured and generally do not qualify for Medicaid. Young adults 19 to 24 years were the most likely age group to be uninsured prior to passage of the ACA and are among those most likely to have pregnancies.<sup>49 50</sup>

Nearly 9 out of 10 women 18-64 years report using some health care services and having some health expenses during a year.<sup>51</sup> Fewer uninsured, low-income, less educated, and Hispanic women report using any health services. More than half of uninsured women ages 18-65 reported going without or delaying needed care because they could not afford the cost.<sup>52</sup> In addition, millions of women qualify for Medicaid only during pregnancy and do not have coverage for primary and preventive well-woman visits and preconception care.<sup>53</sup> A smaller number of women have adverse pregnancy outcomes and go without “interconception” (also known as “interpregnancy”) care specifically designed to address risk factors and prevent a subsequent adverse pregnancy outcome.<sup>54 55</sup>

ACA will provide coverage to millions of uninsured women, which creates an extraordinary opportunity to improve women's health not only during pregnancy, but before, between and beyond pregnancy.<sup>56 57 58 59</sup> The ACA aims to provide affordable coverage for all, with subsidies to those whose income is less than 400 percent of poverty (roughly \$43,320). Increased coverage during the reproductive years could increase access to a range of services and, in turn, improve both the health of women and the outcomes of any pregnancies they may choose to have.

### **Recommendations:**

#### **1.A. Monitor coverage and promote use of women's clinical preventive services.**

The ACA provides an ideal opportunity to promote use of clinical preventive services for women. In August, 2012, an estimated 47 million women gained greater control over their health care and access to eight prevention-related health care services. Of great importance is increased access to well woman visits, including prenatal and preconception care, without cost sharing, which can reduce risks prior to and during pregnancy. The other preventive services in the new HHS guidelines for women's preventive services (i.e., screening for gestational diabetes, HPV DNA testing, domestic violence screening and counseling, HIV screening and counseling for sexually transmitted infections, breastfeeding supplies, contraceptive methods and family planning counseling) are also important for improving women's health and reducing infant mortality.

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*"Defining appropriate preventive services for women and ensuring that those services can be accessed without cost sharing are important strategies to improve women's health and well-being.... Furthermore, mounting evidence suggest that women not only have different health care needs then mend (because of reproductive differences) but also manifest different symptoms and responses to treatment modalities. Behavioral factors that are shown to contribute to morbidity and mortality in women, include smoking, eating habits, physical activity, sexual risk-taking, and alcohol use. Pregnancy and childbirth also carry risks to women's health including maternal mortality. (IOM, 2011, page 1*

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### **1.B. Partner with professionals to develop clinical guidelines for well-woman visits.**

To ensure effective implementation of the federal policy guidelines for coverage with no cost sharing, SACIM recommends that the HRSA Maternal and Child Health Bureau (MCHB) partner with the American College of Obstetricians and Gynecologists (ACOG), American Academy of Family Physicians (AAFP), American College of Nurse Midwives (ACNM), Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN) and other professionals to develop clinical guidelines for providers of well woman visits, including specific guidance for preconception care. The Mikulski "Women's Health Amendment" calls for HRSA to develop such guidelines, and a partnership with providers would enhance their credibility and likelihood of their use. Such an effort would build upon the successful approaches MCHB used in creating *Bright Futures for Children* in collaboration with the American Academy of Pediatrics (AAP). It could parallel and complement the longstanding success of ACOG and AAP in issuing *Guidelines for Perinatal Care*, which was just released in its seventh edition.<sup>60</sup>

Next year, 2013 is the opportune time to develop a guideline document and tools to support its implementation in well woman visits. This work would support implementation of the HHS policy guidelines on women's clinical preventive services coverage and should be grounded in the Institute of Medicine (IOM), ACOG's clinical guideline and opinion series, and the report on the content of preconception care for women of reproductive age.<sup>61</sup> Experts would be convened to represent various organizations and perspectives on practice. The resulting clinical guideline would be widely disseminated. Federal leadership can be the force for convening an array of providers and building on the available science. We believe that no one professional organization will be able to convene and lead this work as effectively as HRSA-MCHB.

### **1.C. Use Medicaid innovation, demonstrations, and flexibility to offer states new avenues for delivering effective, evidence-based interventions to women.**

- **Use the Center for Medicare and Medicaid Innovations to demonstrate the effective- ness of new care models.** The *Strong Start* grant opportunity to evaluate the effect of enhanced prenatal care is an important step which SACIM supports. At the same time, more must be done. Future innovations grants projects – perhaps additional phases of *Strong Start* – could demonstrate approaches that span the continuum from family planning through pregnancy and birth to 24 months of interconception care for low-income, high-risk women and infants. Innovation Grant Challenge projects also should include efforts aimed at improved quality in newborn and regional perinatal care.

- **Support States’ use of Medicaid health homes for women of childbearing age with chronic conditions.** For women of childbearing age, such projects might aim to provide an effective, patient-centered medical home for women with two or more chronic conditions (e.g., asthma, obesity, diabetes, substance use disorder, mental health conditions). Each of these conditions increases risk for an adverse birth outcome.
- **Encourage and permit states to finance interconception/ interpregnancy care in Medicaid.** In 2011, Georgia implemented the first Medicaid waiver to focus on interconception care building on a successful Atlanta project. Louisiana has launched an interpregnancy care waiver project in high-risk areas of New Orleans.<sup>62</sup> Other states are seeking State Plan Amendments and CMS approval for projects that do not require waivers. Permitting state action now can help inform Medicaid coverage expansions in 2014 and beyond.<sup>63</sup>
- **Require that states cover the HHS approved women’s clinical preventive services to women enrolled in Medicaid without cost sharing.** While millions of privately and newly insured women will have no-cost coverage for the clinical preventive services discussed above, the HHS guidelines do not apply to women with traditional Medicaid coverage. This omission in the ACA should be corrected by HHS. Every state Medicaid agency should be required to provide coverage for clinical preventive services without cost sharing.
- **Continue to give states flexibility in design of family planning waivers and state plan amendments which emphasize prevention, well-woman care, and preconception health.** The ACA women’s clinical preventive services coverage without cost sharing will increase access to family planning services. In addition, however, Medicaid policy should continue to support access to family planning services. Medicaid has become one of the largest sources of financing for family planning services delivered to low-income women. As Medicaid is expanded, coverage for family planning should be ensured.

#### **1.D. Increase efforts to ensure access to mental/behavioral health and social support services for women.**

Depression, anxiety, stress, and other psychosocial factors affect the health of women and their pregnancy outcomes.<sup>64 65</sup> Interventions — including individual clinical treatment and community-based strategies — exist to address these psychosocial risks. Increased social support and resilience also can mediate the impact of psychosocial risk factors.<sup>66 67 68</sup>

Depression is widespread, particularly among low-income women. Parental depression and related disorders contribute to adverse pregnancy outcomes and infant morbidity and mortality,

and there are challenges in selecting the most appropriate clinical management course for depression during pregnancy to optimize maternal health and minimize fetal risk. As many as 15 million children, or one out of every five, live with an adult who had major depression in the past year.<sup>69</sup> An Urban Institute study, which for the first time uses a national dataset to look at maternal depression, showed a strikingly high rate of depression. One in nine infants in poor families (i.e., living below the federal poverty level) has a mother reporting severe depression symptoms.<sup>70</sup> More than half of all infants in poor families have mothers reporting some form of depression, including mild and moderate depression symptoms.<sup>71</sup> Moreover, maternal depression frequently coincides with other conditions and risk factors, including other mental health diagnoses, substance abuse, chronic medical conditions, and domestic violence. Unfortunately, while maternal depression can be treated effectively with medication, psychotherapy, behavioral, or other therapy, many low-income women do not receive such interventions.<sup>72 73 74</sup> While brief screening tools are available for primary care and other settings, lack of health coverage and limited availability of providers have been longstanding barriers to treatment for postpartum/maternal depression and anxiety.<sup>75</sup>

Domestic violence and interpersonal violence (DV/IPV) also place women and infants at risk. Pregnant women who experience DV/IPV are at risk for personal harm and increased risk adverse pregnancy outcomes. DV/IPV is associated with: inadequate prenatal care, physical trauma, stress, depression,<sup>76</sup> other high risk behaviors (e.g., substance abuse, tobacco use). DV/IPV is also associated with an elevated risk of homicide as a cause of maternal death.<sup>77</sup> Some studies show an increased risk for preterm and low birthweight births among women exposed to DV/IPV.<sup>78</sup>

Substance abuse is another behavioral health factor related to women's health, pregnancy outcomes, and infant mortality. The incidence of substance abuse in pregnancy is estimated to be 15% to 20% in some communities and is associated with higher risks of preterm birth and infant mortality.<sup>79</sup> Screening and treatment for substance abuse during pregnancy is important for reducing the impact on mother and infant. As substance abuse a chronic relapsing disorder, the goal should be to provide treatment and related interventions sufficient to reduce the impact of substance abuse on pregnancy and the first years of life when a child's safety, security, attachment, and brain development are fundamental to health and well-being for a lifetime. For example, substance abuse case management or home visiting models can connect pregnant women and new mothers to treatment, improve parenting skills, and protect the safety of an infant.



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*“Biomedical risks, such as complications of pregnancy, concomitant maternal disease, infection, nutritional deficiencies, and exposure to teratogens, are estimated to account for approximately one half of the incidence of low-birth-weight infants and of prematurity and their postnatal sequelae. An important portion of the remaining cases of these adverse pregnancy outcomes may be attributable to psychosocial stress even after controlling for the effects of recognized soci-demographic, obstetric, and behavioral risk factors.” ACOG Committee Opinion. #343. Obstet Gynecol. 2006 August; 108(2): 469-477.*

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SACIM recommends support for clinical, public health, and community action to improve mental/behavioral health and social support services. HSS should:

- **Fully fund and implement the provisions of the ACA related to postpartum depression and psychosis, including research, grants to states, and public education campaigns.** The ACA calls for “to continue activities on postpartum [conditions]...including research to expand the understanding of the causes of, and treatments for, postpartum conditions.”
- **Use the resources of the Substance Abuse and Mental Health Services Administration (SAMHSA) to increase knowledge of and access to appropriate screening and treatment for mental and behavioral health conditions** affecting women of childbearing age, before, during, and beyond pregnancy.
- **Monitor coverage for and use of DV/IPV screening and counseling as part of the federal guidelines for women’s clinical preventive services.**
- **Give priority to the development of research and services to reduce substance use among women of childbearing age through NIH and SAMHSA.**
- **Encourage states to use Community Transformation Grants (CTGs) to address the chronic disease risks and needs of women of childbearing age.** Without specific direction related to maternal and child health, many grantees have not partnered or focused on women of reproductive age and/or children. More explicit guidance to states is needed, especially related behavioral health and psychosocial issues.



## **Strategic Direction 2. Ensure access to a continuum of safe and high-quality, patient-centered care.**

Assuring the safety and quality of services for pregnant women and infants throughout the first year of life is a fundamental and essential strategy. Currently, federal and state initiatives, as well as projects in select hospitals and health systems demonstrate what can and should be done. Still, unequal treatment by race/ethnicity, income, and type of coverage has been a persistent problem. Across communities and providers, there is wide variation in applying the best evidence and delivering best practice. In other words, we have far to go toward assuring that all women and infants receive quality care as defined by the Institute of Medicine, that is, safe, timely, effective, efficient, equitable, and patient-centered.<sup>80</sup>

There are missed opportunities for reducing infant mortality and adverse birth outcomes through high-quality maternal and infant services that focus on preventive services, chronic conditions, and mental and behavioral health before, during and after pregnancy. Enhanced and individualized prenatal care is critical. More pregnant women and infants should benefit from birth-related services in a risk-appropriate facility. Prevention efforts should not stop at birth. Quality improvement projects, public and private, are needed to fill the gaps between what we know and what gets done (e.g., elimination of early elective deliveries, appropriate use of progesterone for prevention of preterm birth, screening for asymptomatic bacteriuria or GBS, promotion of smoking cessation, safe sleep or breastfeeding, reducing of central-line associated bloodstream infections in newborns, etc.).

Better care can lead to better outcomes and lower costs. For women of childbearing age and infants, as for other populations, the United States can achieve a high-value, high-performance health system by pursuing the “triple aim”, that is, simultaneously aiming to improve individual experience of care; improve the health of populations; and reduce the per capita costs of care for populations.<sup>81</sup>

### **Recommendations:**

#### **2.A. Strengthen state leadership and capacity to improve birth outcomes and reduce infant mortality through HRSA’s Collaborative Innovation and Improvement Network (COIIN).**

Building on momentum generated by state health officers, the March of Dimes, and other leaders in 13 southern states which had developed state plans to reduce infant mortality, HRSA-MCHB has launched a Collaborative Improvement and Innovation Network (COIIN) to reduce infant mortality in the 13 Southern States of Regions IV and VI. The COIIN builds on the success of the Infant Mortality Summit held in January 2012, at which the 13 states in Public Health Regions IV and VI developed plans to reduce infant mortality. In response, HRSA-MCHB, in

partnership with the Association of State and Territorial Health Officials (ASTHO), the March of Dimes, CityMatCH, Association of Maternal and Child Health Programs (AMCHP), as well as Federal partners including the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare & Medicaid Services (CMS), launched the COIIN to facilitate collaborative learning and adoption of proven quality improvement principles and practices across these 13 states to reduce infant mortality and improve birth outcomes.

Five shared priority strategies were defined in the southern states. The current five COIN strategies are: 1) eliminating elective deliveries prior to 39 weeks gestation; 2) prenatal smoking cessation; 3) safe sleep for infants; 4) Medicaid financed interconception care for women with a prior adverse pregnancy outcome; and 5) strengthened regional perinatal care systems. Each of these COIIN strategies links to other national public and private initiatives, as well as to the recommendations elsewhere in this report.

Multi-state teams, supported by experts, have formed around each of the five strategies. More than two hundred committed professionals from the Southern States are volunteering their time and expertise to the COIIN. Together, these leaders are focusing on ways to ensure health equity, eliminate health disparities, and implement best programs, policies, and practices to reduce infant mortality.

Plans are underway to expand the Infant Mortality COIIN Initiative nationwide. Discussions have already begun in the Midwest (Region V) whose states attended the meeting in July, 2012 as observers and learners. The Mid-Atlantic (Region III) states also have begun planning. Notable, additional regions are discussing additional strategies (e.g., focus on social determinants of health, breastfeeding).

SACIM recommends that resources be made available for HRSA-MCHB to continue the infant mortality COIIN initiative, which engages federal, state, and local leaders, public and private agencies, professionals and communities in advancing priority strategies for reducing infant mortality and improving maternal, infant, and family health. Resources should also be sufficient to support dissemination and spread of best practices.

## **2.B. Use Medicaid to drive quality and improve the health of women and infants.**

As mentioned above, even prior to enactment of the ACA, an estimated 40-50% of U.S. births were financed by Medicaid. With implementation of ACA, Medicaid will become an even more important source of coverage for women and infants. We believe that Medicaid provides the single most important lever HHS has to improve birth outcomes and infant survival for low-income families.<sup>82</sup> Because it is a large payer, changes in Medicaid maternal and infant policy can, in turn, affect the quality of care received by families with other sources of health coverage.

The Strong Start for Mothers and Newborns launched by the Center for Medicare and Medicaid Services (CMS), Center for Medicare and Medicaid Innovation (CMMI) is an important first step. The Strong Start initiative supports reducing the risk of significant complications and long-term health problems for both expectant mothers and newborns. Strong Start's two strategies could each be used to reduce infant mortality beyond the current focus on prenatal care.

One Strong Start strategy is a public-private partnership to increase public and professional awareness of the risks associated with elective deliveries prior to 39 weeks gestation. This work should be continued. A subsequent campaign might focus on increasing public awareness of the warning signs of serious illness or complications among pregnant women and infants (as discussed below).

The other Strong Start strategy is a funding opportunity for testing new approaches to care. In 2012, this funding was focused on prenatal care. Prenatal care was a good place to begin expanding our knowledge about what works in Medicaid to improve birth outcomes. Understanding the role of group care and other prenatal enhancements is important. But, prenatal care is only one part of the continuum of services that help mothers and babies have optimal health and outcomes.

**SACIM believes that additional CMMI funding opportunities, perhaps as subsequent phases of Strong Start, should be used to address other key facets of infant mortality prevention, including but not limited to:**

- approaches to strengthen regional perinatal care systems
- enhanced approaches to interconception care for women who have had a prior adverse pregnancy outcome financed by Medicaid, particularly those with chronic diseases
- improved methods for hospital discharge planning and transitions to community care, especially for infants with special health care needs and for skills support of mothers who are breastfeeding
- appropriate services for low-risk women attended at birth by nurse-midwives
- innovation in screening and treatment for maternal depression and related mental disorders.

**SACIM also recommends that CMS, particularly CMMI, use its resources to encourage testing and expansion of innovative models for service coordination and systems integration.** This might include projects focused on improving services for women and infants through “integrated care models”, which include medical/health home, accountable care organizations (ACO), ACO-like models, and other arrangements that emphasize patient-centered, continuous, coordinated, and comprehensive care. In the community, approaches include: accountable care communities, community-based collaborative care networks, community health teams, patient navigators. CMS has offered guidance to states in designing

and implementing such health care delivery reforms; however, more specific attention to the risks and needs for families in their childbearing years is warranted.

Various patient-centered medical home (PCMH) initiatives sponsored through the CMMI are testing alternatives to the traditional primary care delivery system, with a team approach to primary care that may allow physicians and other health providers to serve more patients more effectively. CMS could encourage states and other entities to develop projects that focus on the role of the medical/health home in improving the health of women and infants. Current demonstration projects are linked to quality measures such as NCQA certification, and more focused efforts have the potential to drive development of better perinatal safety and quality programs in primary care settings.

## **2.C. Support quality improvement activities through other agencies of HHS, including the Agency for Healthcare Research and Quality (AHRQ) and CDC.**

**SACIM recommends continued emphasis and support to AHRQ for improving the quality of perinatal services.** The mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. Information from AHRQ's research helps people make more informed decisions and improve the quality of health care services. AHRQ's work focuses on five areas: 1) quality improvement and patient safety; 2) comparing the effectiveness of treatments; 3) prevention and care management; 4) health care value; and 5) health information technology. The agency produces information intended to: reduce the risk of harm from health care services, transform the practice of health care to achieve wider access to effective services and reduce unnecessary costs, and improve health care outcomes. AHRQ has developed quality indicators and other tools for use in programs, clinical settings, and research, conducts evidence reviews, and produces reports to document trends in health care quality. Women and children are priority populations for their work. In terms of perinatal care and quality, AHRQ has supported a wide array of projects on a variety of topics (e.g., postpartum depression, pregnancy warnings, bacterial vaginosis in pregnancy, breastfeeding, elective induction of labor, preterm birth prevention, gestational diabetes, folic acid, maternal weight gain, regionalization of perinatal services, and community-based participatory research to address disparities). The agency produces materials for consumers and professionals (e.g., clinicians, payers, researchers, health administrators, and policymakers).

**SACIM recommends continued support to CDC for reproductive health, preconception, birth defects prevention, adolescent pregnancy prevention, and other activities related to reducing infant mortality and improving birth outcomes.** CDC's work on a strategic plan on women's health and an action plan on preconception health and health care has identified opportunities to improve the quality and effectiveness of services for women and infants. In

addition, further study is needed to identify effective communication, public health, and clinical strategies that can increase reproductive health awareness and life planning, prevent birth defects, prevent pregnancy among adolescents, support healthy weight gain during pregnancy, eliminate alcohol use during pregnancy, protect from environmental and occupational hazards, enhance social support, and otherwise reduce risks related to reproductive health, pregnancy, and infancy. New knowledge in these and related areas should be widely disseminated to improve the quality of clinical and community-based services.

**SACIM recommends continued federal investments to support national and state-level quality improvement collaboratives and tools for learning** (e.g., California Perinatal Quality Collaborative toolkits, toolkit on implementing the Joint Commission Perinatal Care Core Measure on Exclusive Breast Milk Feeding, Child Health Improvement Projects). Data-driven quality improvement can improve maternal and neonatal outcomes through multi-stakeholder quality collaboratives, statewide perinatal outcome databases, projects efforts to achieve data quality, and the use of data to drive and incentivize quality care. New ideas are being tested in all of the States, but implementation of best practices is slowing and progress is uneven.

Federal support should be made available for state and multi-state perinatal quality collaboratives. Such efforts will take quality improvement beyond the random chance of which provider a family uses to more uniform quality care. Funding might be provided through HRSA, CDC, AHRQ, CMS, or other federal agencies and programs.

## **2.D. Support health coverage for all newborns by requiring newborn coverage for all infants (i.e., with public or private coverage) and making temporary coverage available to those who are uninsured at birth.**

Health coverage is strongly associated with newborn health and survival. In line with the goals of ACA, the HHS should make automatic newborn coverage a feature of the health system beginning in January 2014.

Under current federal law, states are required to automatically enroll newborns in Medicaid if their birth has been financed by Medicaid. The automatic newborn coverage rule has been a feature of Medicaid since 1986. States use a variety of mechanisms to ensure that infants who are entitle to Medicaid from the moment of birth are not exposed to the possibility that they will be treated as ineligible for Medicaid because they lack evidence of coverage. With implementation of the ACA, the nation should make a commitment to continuing this policy of assuring that all newborns have evidence of coverage from the moment of birth. For infants covered through private plans, this typically involves adding the baby to the coverage unit at the time of birth upon verification. For babies born into families enrolled in Medicaid, current state practices should continue. In addition, states would be required to automatically enroll and provide coverage through Medicaid to any infant who is otherwise uninsured at the time of birth

(i.e., not yet eligible because the mother lacks any form of public or private health insurance). As with current automatic newborn eligibility, such Medicaid coverage, a temporary period of automatic enrollment rule would be followed by the issuance of more permanent evidence of coverage, as needed.

## **2.E. Maximize the ACA investments in community health centers and workforce capacity.**

For women, infants, and families to receive high quality patient centered services throughout the continuum of perinatal care requires both a place for this care and the healthcare workforce to deliver the care. The ACA has several provisions to expand community health centers (CHCs, also known as Federally Qualified Health Centers – FQHCs) and to expand the primary care workforce for these centers. From the perspective of infant mortality reduction, such expansion is essential because CHCs and their primary care providers offer both comprehensive primary care and perinatal and reproductive health care to low-income women and families in underserved communities with significant health disparities in maternal and infant care.

A dedicated fund for health center expansion has thus far supported nearly 200 construction and renovation projects at existing CHCs as well as creation of dozens of new CHCs nationally.<sup>83</sup> The ACA will fund hundreds more such projects by 2014. These renovations and expansions will enable CHCs to locate their essential primary care services in the communities most at need for this care and with high need for quality prenatal care and infant care.<sup>84</sup>

In addition to supporting CHC expansion in both facilities and electronic health technology, the ACA also includes provisions to increase the supply of providers available to staff these health centers. With thousands of currently unfilled provider positions in CHCs, and a target of one provider for every 2,000 patients, HRSA estimates that an additional 17,722 primary care practitioners are already needed in shortage areas across the country with another 35,000 to 44,000 adult primary care providers potentially needed by 2025. The ACA's investment in expanding the primary care workforce focuses on increasing the supply of practitioners through educational loan forgiveness or scholarships, training expansion, higher payment rates, and credentialing. New funding for the National Health Service Corps provides loan repayment and scholarships for health professional students who work in CHCs. Several programs aim to increase the pipeline of dedicated primary care training, including: CHC grants to train resident physicians in the community, programs to encourage students to enter primary care (as physicians, advanced practice nurses (APNs), and physician assistants), and incentives for loan reduction for medical students to choose primary care in rural and underserved areas. Specific ACA provisions promote the training and use of APNs in primary care. ACA also created incentive payments to eligible primary care physicians in states' Medicaid programs.



**SACIM recommends that HHS:**

- **Maintain the ACA multi-billion dollar commitment to expansion of community health centers.** (CHCs, also known as federally qualified health centers—FQHCs—under the Medicare and Medicaid programs). CHC/FQHCs are experts in delivering care in a patient-centered medical home, with teams of providers and address both the medical and social determinants of health. The comprehensive primary care delivered by CHC/FQHCs can help to reduce racial/ethnic and income disparities in infant mortality.
- **Maximize opportunities in the ACA to improve the primary care and public health workforce.** These include investments in training for primary care physicians, nurses, the public health workforce, and community health workers. Such investments will generate the workforce needed to care for women, infants, and families.
- **Include OB-GYNs in the list of providers eligible for Medicaid primary care incentives payments.** As many as half of women of childbearing age consider their OB-GYN to be their primary provider or medical home. Millions receive their well-woman visits from OB-GYNS. These physicians also provide a majority of prenatal care visits to women covered by Medicaid. Permitting OB-GYNs to receive primary care incentive payments through Medicaid will help to maintain access to this pool of providers.

**Strategic Direction 3. Redeploy key evidence-based, highly effective preventive interventions to a new generation of families.**

A variety of prevention strategies have the potential for positive impact on birth outcomes and infant survival. Some — such as prenatal, preconception, and well-baby care — are clinical care processes that provide opportunities to offer evidence-based interventions and health promotion. Others — such as prevention of injury and environmental exposures — depend upon an array of health promotion, social marketing, and modifications to the home or community environment. SACIM has identified five discrete preventive interventions which are proven effective and need to be redeployed to reduce infant mortality, particularly to have impact on postneonatal mortality and morbidity. SACIM also believes that additional messages are needed to help families identify warning signs of serious conditions and that ensuring coverage for newborns will help to reduce preventable infant deaths.

### **3.A. Design and implement new health promotion and social marketing campaigns to accelerate use of five key preventive interventions.**

Evidence suggests that some of the most effective, proven infant mortality prevention strategies are not being effectively communicated to and used by families giving birth to the next generation.<sup>85</sup> Immunization levels are low in some communities, and an increasing number of families are misinformed about their safety and benefit.<sup>86</sup> Breastfeeding levels are below our national objectives, and lowest among younger mothers.<sup>87 88 89</sup> While infant mortality was reduced with a highly effective “Back to Sleep” campaign, many new parents do not have the message or engage in safe sleep practices and current messages do not appear to be equally effective across socio-cultural groups.<sup>90 91 92 93</sup> Rates of tobacco use are down; however, the benefits of smoking cessation are particularly great during the prenatal period and when a young child is in the home.<sup>94 95</sup> Family planning has been shown to have direct impact on infant mortality by increasing the number of pregnancies timed for optimal outcome and reducing the number of unintended pregnancies and abortions.<sup>96 97</sup> At the same time, many women have limited access or use less effective methods.<sup>98</sup>

**SACIM recommends that HHS give particular emphasis social marketing, health education, and access to clinical and community preventive services for the following five interventions** which have proven effectiveness and are not being used to achieve maximum levels of prevention.

- Immunization
- Breastfeeding (see Appendix F)
- Safe sleep to prevent SIDS/SUID
- Smoking cessation during pregnancy and for new parents
- Family planning

For more than fifty years, researchers have broadened our understanding of how to help individuals understand health influences and risk factors, become motivated to strive for optimal health, and make lifestyle changes to optimize their health.<sup>99 100</sup> Health promotion can be an effective strategy to modify individual behaviors that affect health. Social marketing and risk communication campaigns can influence opinions of larger numbers of individuals. Health promotion and social marketing to reduce infant mortality encompasses a wide array of topics, including, but not limited to: reproductive life and pregnancy planning, preconception health, folic acid, substance use, environmental exposures, healthy weight, preterm birth, safety and unintentional injuries, and nutrition.<sup>101</sup> While health promotion and social marketing strategies can be effective, they do not always work and must be tailored to audiences.



In addition, the world has changed in terms of communication and social networking. Using new technologies, platforms, and modalities will be essential to the success of updated health promotion and social marketing campaigns designed to prevent more infant deaths. Text4baby, based on a public-private partnership, is one example. Text4baby has high levels of acceptance and satisfaction and growing evidence of increases in health knowledge. It also has 46 percent of enrollees signing up in the first trimester of pregnancy and a demonstrated capacity to engage women in high-poverty communities.<sup>102</sup> More campaigns using modern technology are needed to reach additional families with health promotion and prevention messages.

**SACIM recommends that, for the five preventive interventions listed above, HHS develop new research-based, 21<sup>st</sup> century social marketing campaigns, health promotion materials for use by individuals, and support for dissemination of such communications.**

We anticipate that these new social marketing and health education efforts will be accompanied by increased need for access to services. Increased demand for these preventive interventions is supported by the ACA through increased coverage without cost sharing for clinical preventive services, investments under the Public Health and Prevention Fund for community preventive services, and increased access to primary care and medical/health homes. These elements of a national strategy are addressed elsewhere in this report.

### **3.B. Conduct health promotion and social marketing campaigns to inform families about the warning signs of pregnancy complications and infant risks and the actions families should take when problems arise.**

Whether due to lack of information, health literacy, or other barriers, many families in their childbearing years do not understand key warning signs of pregnancy complications (e.g., certain infections, preterm labor) or serious signs and risks for infants (e.g., fever, severe respiratory infections, crying). More should be done to ensure that pregnant women and families with infants gain high levels of knowledge and awareness of common warning signs of pregnancy complications and infant risks.

## **Strategic Direction 4. Increase health equity and reduce disparities by targeting social determinants of health through both multi-sector investments in high-risk, under-resourced communities and major initiatives to address poverty.**

Persistent racial/ethnic and economic disparities in adverse birth outcomes, infant mortality, and maternal mortality in the United States are a national tragedy. A disproportionate number of African American, Puerto Rican, and American Indian/Alaskan Native infants are born too early,

too small and die in the first year of life. Infants in poor families, of any race/ethnicity, face elevated risks of infant mortality and morbidity. At the same time, the Black-White gap in adverse outcomes actually widens at higher levels of socioeconomic status. Greater economic resources may not be as protective of African American women's reproductive health because Blacks earn less than Whites for a given level of education, support more people with those earnings, have less accumulated wealth, pay more for basic necessities, and are more likely to have suffered economic disadvantage as children during key developmental periods.<sup>103</sup> While immigrant black women's birth outcomes parallel those of non-Hispanic whites, their reproductive advantage erodes with subsequent generations of U.S.-born daughters, a pattern attributed to race-based, social disadvantage.<sup>104</sup>

The underlying causes of health disparities must be specifically tackled with determination. Poverty and other social determinants of health are associated with adverse birth outcomes and infant mortality, such as social-economic disadvantage,<sup>105</sup> unequal treatment,<sup>106 107</sup> institutionalized racism (e.g., residential segregation, policies that create and perpetuate unequal opportunities),<sup>108 109 110</sup> minority status stressors,<sup>111 112 113 114</sup> and income inequities.<sup>115 116</sup> The role of social determinants in shaping the health of mothers, infants, and families is clear and new policies may improve or worsen their impact.<sup>117</sup> While improved access to and quality of health care services are important, they are insufficient for closing the gap.<sup>118 119</sup> For example, pregnant African American women have greater accrued risk for and fewer amassed protections against poor birth outcomes because of the multigenerational social inequities racism produces.<sup>120 121</sup> From a life course perspective, their reproductive health may be compromised well before they ever become pregnant.<sup>122 123 124 125</sup> Reducing disparities and the underlying social and economic factors that drive them must be a top priority in our national strategy for improving birth outcomes and reducing infant mortality.

The HHS Action Plan to Reduce Racial and Ethnic Health Disparities defines major dimensions of the burden of racial and ethnic health disparities: 1) disparities in health care and unequal treatment (i.e., insurance status, access to care, and quality of care received); 2) disparities in the nation's health and human services infrastructure and workforce (i.e., racial/ethnic composition of workforce and other cultural competency and diversity issues); 3) disparities in the health and well-being of women, infants and families (e.g., the health status of individuals and communities); and 4) disparities in scientific knowledge and innovation (e.g., poorly standardized data).

The HHS Disparities Action Plan also defines new opportunities to reduce racial and ethnic health disparities. (Appendix D shows a "crosswalk" between SACIM priorities and the HHS Disparities Action Plan showing parallel strategies and activities.) As in the HHS Disparities Action Plan, SACIM is issuing a strong call for HHS to prioritize action to increase health equity by eliminating racial/ethnic and economic health disparities that lead to infant mortality. The

potential for HHS to take collective action is great. Interagency collaboration across HHS, through HRSA, CMS, CDC, SAMHSA, and NIH is critical to achieving our goals. Likewise, SACIM has outlined the role of partnerships between HHS and other Federal Departments. (See Strategic Direction 6.)

Ensuring health equity will require multiple strategies. Key opportunities for eliminating disparities in infant mortality and other adverse pregnancy outcomes exist in the ACA, through steps to broaden access to coverage, investing in prevention, and specific provisions related to data collection and quality improvement. Many such ACA provisions are reflected elsewhere in this report. In addition, SACIM has identified multi-sector community-based initiatives aimed at increasing health equity and influencing social determinants as an important means to tackle disparities. Transformation of Healthy Start and creation of a new interagency place-based initiative are key recommendations.

Reducing poverty among families in their childbearing years is equally critical to reducing infant mortality. Poverty and many of its sequelae — including poorer health status and decreased access to health care, diminished access to adequate housing, lack of sufficient nutrition, and increased exposure to environmental insults — are important direct correlates of infant mortality as well as risk factors for many of the key causes of infant death including preterm delivery, low birthweight, less breastfeeding, infant homicide, and SIDS/SUID. Poverty during pregnancy is associated with higher prevalence of hardship (e.g., divorce, domestic violence, homelessness, food insecurity, and no social support).<sup>126</sup> As such, addressing growing rates of child poverty in the United States is an essential infant mortality reduction strategy.

Our recommendations aim to increase health equity both by targeting social determinants of health through multi-sector investments in high-risk communities in order to increase access, opportunity and supports, and by accelerating efforts to reduce racism and poverty.

### **Recommendations:**

#### **4.A. Convene an interagency expert panel to set goals for closing infant mortality gaps.**

For both African American and American Indian/Alaska Native infants, the infant mortality rate continues to be 2-3 times greater than for non-Hispanic whites. SACIM recommends that the Secretary convene an interagency panel to set goals for closing these gaps. This panel should identify targets for 2015 and 2020 based upon: historical trends, the potential impact of the ACA and other policies, and the potential impact of SACIM recommendations. A work group of SACIM or another HHS advisory body might serve as the panel.

#### **4.B. Support and transform the federal Healthy Start program and maximize its potential to reduce infant mortality, eliminate disparities, and increase health equity.**

The federal Healthy Start program is designed to reduce the rate of infant mortality and improve perinatal outcomes through grants local areas with high rates of infant mortality. Authorized by the Congress in 1991, the program has grown from 15 grantees to a network of 105 sites across 38 states, the District of Columbia, and Puerto Rico. Healthy Start serves approximately 36,000 women (as well as their babies and fathers) annually,<sup>127</sup> and over 90% of all Healthy Start families are African American, Hispanic, or Native American. Projects operate in urban, rural, tribal and border communities. Healthy Start grantees specifically aim to address racial/ethnic disparities in the health of mothers and babies under-resourced communities that face many challenges, including high poverty, inadequate access to care, and environmental risks.

All Healthy Start grantees provide the following core services: direct outreach and client recruitment, health education, case management, depression screening and referral, and interconception care services for participating families.<sup>128</sup> Healthy Start grantees provide patient-driven, community-based, culturally competent services to promote positive birth outcomes for some of the nation's highest risk, vulnerable women, infants, and families. Healthy Start grantees offer a continuum of health care services and social supports, including coordination and navigation of clinical and non-clinical services for pregnant women, as well as new mothers, and their children (0-2 years old). Trained community health workers are integral to Healthy Start providing services often working in community-based teams with nurses, social workers, and other professional staff.<sup>129</sup>

In addition, each Healthy Start grantee has a consortium composed of program participants, neighborhood residents, health care providers, social service agencies, faith representatives and the business leaders. With these characteristics, it is a forerunner of currently discussed "place-based initiatives".<sup>130 131</sup> With emphasis on community engagement and individual empowerment, the Healthy Start approach increases civic engagement, maximizes social capital, and fosters resiliency in communities by building on strengths and assets.<sup>132</sup>

Healthy Start is designed to improve birth outcomes by promoting positive health behaviors, responding to basic needs, reducing barriers to care, and empowering women to care for themselves and their families.<sup>133</sup> Evaluations indicate success in reducing unmet need for services.<sup>134</sup> Some individual grantee evaluations show promising results; however, program data and evaluations to date have been insufficient to document the full impact of the national set of grantees on birth outcomes.<sup>135 136 137 138 139 140</sup>

**SACIM specifically recommends that HHS:**

- **Continue funding the federal Healthy Start program as a priority initiative to reduce the rate of infant mortality and improve perinatal outcomes** through grants to

project areas with the highest annual rates of infant mortality. Resources should be made available to expand, on a competitive basis, the use of evidence-based practices and demonstrate the effectiveness of promising practices through Healthy Start grantee sites.

- **Through the efforts of MCHB, implement new performance standards, evidence-based interventions, and system building strategies in every Healthy Start community.** New data and evaluation activities should be carried out to further document the impact of Healthy Start’s community-driven, patient-centered, strengths-based, and culturally competent model. A revised and improved data collection and performance monitoring is needed. With new research findings Healthy Start should be re-reviewed as an evidence-based model for the MIECHV program.
- **Consider using Healthy Start grantees as the hub or central coordinators for new place-based initiatives** designed to reduce infant mortality and improve the health of families in their childbearing years.
- **Give approval to Healthy Start grantees who qualify to become patient-centered, community-based health teams** for women, children, and families, which can seamlessly integrate with public health and clinical services. This is parallel to the design of health teams set forth in the Affordable Care Act. In addition, Healthy Start grantees should be engaged in related, community-level implementation of ACA in communities with highest levels of infant mortality and risk (e.g., promotion, navigation, case management, community health workers).

#### **4.C. Use federal interagency collaboration to turn the curve on social determinants of health at the community level by concentrating investments from multiple programs in place-based initiatives.**

Increasingly, local leaders committed to improving health outcomes are focused on “place” and how to bring policy, practices and other resources together within neighborhoods and communities to improve the health and well-being of residents. This interest has led to a range of efforts known as “place-based initiatives,” which are designed to improve outcomes and reduce disparities in high-risk communities by reducing the negative impact of social Determinants. Their aim is to create a community environment that promotes and protects health, while also addressing individual needs and choices.<sup>141</sup> Place-based initiatives can transform communities into more vibrant, integrated, and healthy communities.

Place-based initiatives are premised on three key approaches. The first is to foster community systems change and re-alignment among existing programs and organizations, concentrating the value of existing resources. The second is to improve health through both access to medical care services and by broadly emphasizing health promotion and disease prevention. The third is to

have primary services be linked effectively to specialty or more intensive services for those who need them.

This is not just theoretical. There are promising, even inspirational examples of community (zonal) transformation, helping unite all sectors of a community to build a pathway to success. The “Harlem Children’s Zone” is a notable example. Many other successful child development and health placed-based initiatives exist, including “Opportunity Knocks” or “Help Me Grow” in Connecticut, Boston’s “Thrive in Five” or Oakland, California’s “Building Blocks Collaborative”. In “Best Babies Zones” three communities funded by the W.K. Kellogg Foundation are advancing placed-based initiatives specifically focused on improving birth outcomes and reducing infant mortality.<sup>142</sup>

**SACIM recommends that HHS lead in creation of a new federal interagency project to create place–base initiatives to optimize birth outcomes, reduce disparities, and increase health equity. We also recommend the following steps to help ensure success.**

- **Select a group of 10-25 local geographic areas (i.e., a neighborhood, community, city, or county) with elevated poor birth outcomes and high infant mortality rates.** The overall goal would be to “turn the curve” on the social determinants that underlie high infant mortality rates and adverse reproductive health outcomes in a community. These infant survival zones might overlap conceptually and geographically with federal projects funded through Healthy Start and maximize the potential for projects such as “Promise Neighborhoods” and “Empowerment Zones”.
- **Concentrate federal investment, bringing together all federally supported programs in a community.** These initiatives must be supported by a federal interagency collaboration giving priority for investment to selected communities. The aim is to create synergy and maximize the impact of investments in higher-risk families and underserved communities. Ideally, each community would receive federal funding to host each of the nation’s community-based maternal and child programs, including Healthy Start, Head Start, MIECHV, Project Launch, WIC, community health center, and similar programs. In addition, priority for investments such as child care, education, mental health, housing, transportation, job training, and other services might be created in these communities.
- **Require partnerships with the private sector** (e.g., private providers, businesses, churches, universities, and local philanthropies). The partnerships would play an essential role in this common effort to transform the community.
- **Designate a neutral convener organization (e.g., a community agency, local health department, Healthy Start grantee) committed to a placed-based approach.** Such an entity would facilitate collaboration of all relevant community sectors.



- **Require a local area strategic plan and common goals/metrics.** The specific programmatic details may vary by community, but all partnership organizations would work toward defined community transformation goals, with common metrics and evaluation of progress.

#### **4.D. Address and alleviate poverty, which has a known impact on infant mortality, through enhanced use of income supports through TANF, EITC, and other policies.**

Poverty and many of its sequelae — including poorer health status and decreased access to health care, diminished access to adequate housing, lack of sufficient nutrition, and increased exposure to environmental insults — are important direct correlates of infant mortality as well as risk factors for many of the key causes of infant death including preterm delivery, low birthweight, infant homicide, and SUID. As such, addressing growing rates of child poverty in the United States is an essential infant mortality reduction strategy.

Families of childbearing age are more likely than older families and individuals to have low income. Currently, although children make up 24 percent of the US population, they represent 34 percent of all individuals in poverty. Young children, those under age 6, are particularly vulnerable because they typically have young parents who have lower levels of education and a less a more tenuous relationship to the job market and to well-paying and regular employment than older parents. In 2010, almost half of children under 6 — more than 11 million young children — lived in low-income families (i.e., those with incomes less than 200 percent of the federal poverty level). Of these, nearly 6 million children were poor (living in families with incomes less than 100 percent of the federal poverty level).<sup>143</sup> The national recession further exacerbated the situation for young children as the typically lower educational level of their parents coupled with declining employment rate and stagnant wages increased their likelihood of living in impoverished families. Overall, the child poverty rate rose during the first three years of the current economic recession (2008-2010) and remained constant in 2011 at 22 percent.<sup>144</sup>

Unfortunately, the nation no longer has a strong, coordinated anti-poverty strategy. One program that is designed to address poverty, the Temporary Assistance for Needy Families (TANF) is no longer serving as an adequate safety net to address poverty. In fact, while the national TANF caseload declined between 1995 and 2010, the number of families with children in poverty increased by 17% during this time period, from 6.2 million to 7.3 million. In 1995 TANF's predecessor, Aid to Families with Dependent Children (AFDC) lifted 62% of very poor children out of poverty; however, in 2005, TANF lifted only 21% of very poor children out of poverty.<sup>145</sup> So while the TANF Block Grant has been effective in its objective to remove families from the welfare "rolls", it has not been effective in moving families out of poverty. TANF's strengths and weaknesses as an anti-poverty program have been debated since its inception and although it is not the place of this report to provide specific recommendations on the many nuances of



TANF including the contingency fund, changes in what can be counted as work, and use of performance measures such as the work participation rate, we believe all of these aspects of the TANF Block Grant deserve attention from the Secretary of DHHS.

**For TANF, SACIM recommends that the Secretary of DHHS:**

- **Document and report on the TANF’s effectiveness as a safety net for poor children in each state.**
- **Require states to spend a specific portion of their TANF funds directly supporting families in need with either cash assistance or subsidized employment.**
- **Study the impact of current policies on the population of women with young children who have reached their time limits and now fall into the category of “no welfare, no work”.**

In addition, to move the nation toward greater support for poor families in their childbearing years, **SACIM recommends that the Secretary work with the US Department of Labor and the Internal Revenue Service to:**

- **Expand the Earned Income Tax Credit (EITC) to families who do not work (and have demonstrated they are unable to work or cannot find work)**
- **Work with states without an EITC or a refundable EITC to implement a state-level refundable EITC by 2016**
- **Allow poor families with no tax liability to receive the Child Tax Credit**
- **Invest in state demonstration projects for Children’s Savings Accounts**
- **Advance policies in support of paid family medical leave, particularly paid maternity leave for new mothers<sup>146</sup>**
- **Convene a commission to explore the development of a national Children’s Allowance program.**

**4.E. Add SACIM to list of HHS Initiatives aiming to eliminate disparities and increase health equity.** While many agencies and entities are listed in the HHS Disparities Action Plan, SACIM is not. We believe our charter and our history place SACIM among those entities aiming to eliminate disparities and increase health equity.

## **Strategic Direction 5. Invest in adequate data, surveillance systems, and research to measure health care access, quality, and birth outcomes.**

Timely and accurate data are needed to help inform the most important policies and programs for families across the country. Collecting, analyzing, and applying the knowledge from a wide range of data will help to define the extent, causes, and contributors to infant mortality and poor birth outcomes.<sup>147</sup> Some information comes from surveys, some from clinical practice, and still more from special, focused studies. Without such data, we cannot understand the problem, monitor trends in service utilization, and use data for quality improvement. No one data system can supply what is needed even to address infant mortality; the nation needs multiple data systems working in a coordinated and linked fashion where possible. Having accurate data depends on public health professionals, clinical care providers, health plans, and state and federal agencies, as well as individuals who give their permission for personal information to be used for scientific purposes.

SACIM is concerned that several important data, monitoring, and surveillance systems that are needed to inform the nation's infant mortality strategy are in disrepair or seriously underfunded. HHS leadership is critical to repairing, supporting, and funding these systems.

In addition, throughout the 20 years, SACIM panels have called for additional research and we renew that call. There is no question that further research is needed to understand the causes of and opportunities for prevention of infant mortality, maternal mortality, birth defects, preterm birth, SIDS/SUID, and other adverse pregnancy outcomes.

### **Recommendations:**

#### **5.A. Make investments in the National Vital Statistics system to assure timely, and accurate birth and maternal and infant death statistics.**

The National Center for Health Statistics (NCHS) works collaboratively with states and territories, through the National Vital Statistics Program to help ensure the publication of data that best reflect the experiences of families that experience pregnancies, live births and fetal and infant deaths in the United States. Lack of universal adoption of the 2003 Standard Birth Certificate has created a fragmented system of birth data, severely limiting its usefulness in identifying national priorities for perinatal health.

In 2003, NCHS issued a revised U.S. Standard Live Birth Certificate which updated the previous one issued in 1989. Whereas the 1989 Standard Certificate of Live Birth was adopted by all jurisdictions within two years, the 2003 Standard was adopted by only 13 jurisdictions within two years.<sup>148</sup> By 2012, more than 8 years later, 13 states are still using the 1989 standard.

One primary reason for the lack of universal adoption of the 2003 Standard has been that federal funding to states to support implementation and training for the Vital Statistics system has remained constant over the past decade. SACIM recommends that HHS commit the necessary resources to support adoption of the 2003 Standard Birth Certificate by all jurisdictions.

SACIM emphasizes the foundational and central role of the birth certificate in assessing and improving maternal and infant health outcomes. Birth certificate data should be made consistent across states, rapidly available to drive health services and quality, and linked to other data sources.

#### **5.B. Incentivize reporting of Medicaid perinatal data from every state, based on a uniform set of quality and outcome measures.**

While nearly half of all births are financed by Medicaid, no national Medicaid perinatal data set exists. For infants, reporting on the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program provides utilization data regarding well-child visits. No similar national data set exists to measure utilization of prenatal care, birth services, newborn care, and postpartum visits. No uniform approach to defining or counting Medicaid births exists today. Reporting on some measures is done by managed care organizations participating in Medicaid; however, this is much less than the full population and not uniform in scope across states and plans. Moreover, no uniform reporting on outcome measures is underway. Nationwide reporting of Medicaid perinatal data would allow for the identification of gaps in the program as well as areas where the program is performing well in meeting the needs of families.

In 2012, the CMS Center for Medicaid and CHIP Services (CMCS) convened an Expert Panel on Improving Maternal and Child Health Outcomes. This is an important step in the right direction. SACIM members, along with other invited experts, are engaged in discussions about what to measure, what is feasible for states to measure, and best practices in measurement. They are focused on an array of topics such as measurement strategies for prenatal care, preterm births, neonatal conditions, newborn screening, postpartum visits, and preconception care/well-woman visits. The CMS Expert Panel also intends to make recommendations for quality and performance measures.

**SACIM specifically recommends that CMS define a perinatal data set in partnership with states and that incentives be given to States to collect and report a newly defined, uniform set of perinatal quality and outcome measures.**

#### **5.C. Provide resources to expand the Pregnancy Risk Assessment and Monitoring System (PRAMS) to every state in order to monitor the health of women and infants.**

PRAMS is a surveillance project of the CDC and state health departments. PRAMS includes state-specific, population-based data on maternal attitudes and experiences before, during, and

shortly after pregnancy. PRAMS data are not available from other sources and can be used to identify groups of women and infants at high risk for health problems, to monitor changes in health status, and to measure progress towards goals in improving the health of mothers and infants. Current PRAMS states have used the data to inform legislative and programmatic efforts, including support for breastfeeding policies and initiatives (<http://www.cdc.gov/prams/>). As of this writing, 40 states and New York City currently participate in PRAMS (78% of live births). SACIM recommends that funding be made available to the remaining states and the District of Columbia to conduct PRAMS.

#### **5.D. Systematic use of quality measures for women and children.**

With development and approval of measures by the AHRQ and the National Quality Forum, as well as other entities, the opportunity for more routine use of quality measurement throughout the health care system is not only feasible but an imperative. The National Quality Forum perinatal care quality measures are a starting point but more can and should be done.<sup>149 150</sup> The ACA called for increased emphasis on quality measurement for both children and adults, and many projects are underway to fulfill new mandates or adopt new measures. The Children's Health Insurance Program Reauthorization Act (CHIPRA) also called for new child health measures. Public-private collaboration is underway through partnerships with professional associations (e.g., American College of Obstetricians and Gynecologists "reVITALize" project, Medicaid Medical Directors Learning Network), as well as state level perinatal quality collaboratives.<sup>151</sup>

**SACIM specifically recommends that HHS:**

- **Widely disseminate AHRQ/NQF measures to help promote their adoption in practice.**
- **Continue to engage in and support actions by CMS, HRSA, AHRQ, and other agencies that will improve the consistency, accuracy, and utilization of quality measures.**
- **In addition to the eMeasure initiative for extracting quality measures from electronic medical record, develop a similar eBirthCertificate process to ensure that Vital Records clinical data are at the highest level of quality.** Such a process would give attention to formal electronic specification that permit more effective and efficient use of birth certificate data in the context of electronic medical records. This should be included as part of "meaningful use" projects.

**5. E. Continue support for other related data systems, including: Title V Information System (TVIS); MIECHV data; National Immunization Survey; Behavioral Risk Factor Surveillance System (BRFSS); Fetal-Infant Mortality Review (FIMR); newborn screening data; and the National Birth Defects Prevention Network and state-based birth defects surveillance.**

Each of these data systems collect unique and important data for use in program and policy decisions. SACIM recommends that funding for these programs should increase commensurate with agency recommendations. In addition, we encourage investment in linked data activities, particularly linkages between vital records and related maternal and child health data.

**5.F. Give priority to research into the causes and prevention of infant mortality through NIH, AHRQ, HRSA, CDC, CMS, SAMHSA, and other parts of HHS.**

Continued investment in research has been recommended by SACIM for the past 20 years. Some progress has been made, but additional effort is needed. Research investments must move beyond a focus etiology to include investments focused on best practices, as well as innovation and translation. The nation needs to support basic research, translational research, health services research, research related to quality, and participatory action research to illuminate causes, barriers, and solutions for the problem of infant mortality.

Research should be supported through various units of HHS and efforts should be coordinated to maximize resources and impact. For example, NIH, CDC, and HRSA are all conducting and/or supporting research related to preterm birth, SIDS, birth defects (congenital conditions and heritable disorders), child injury, child maltreatment, and other related issues. The National Children's Study — one of the richest research efforts designed to study children's health and development — is led by the NIH in collaboration with a consortium of federal partners including CDC, HRSA, and the Environmental Protection Agency (EPA).

## **Strategic Direction 6. Maximize the potential of interagency, public-private, and multi-disciplinary collaboration**

The SACIM recommendations in this report reflect our knowledge and certainty that reducing infant mortality in the United States will require a multi-faceted effort, including integration of clinical care and public health into comprehensive systems of care, practice improvement by service providers, changes in knowledge, attitudes and behaviors of men and women of childbearing age, improved access to health care, empowered communities, health equity, and a

serious commitment to prevention. We cannot achieve our infant mortality reduction goals by working in silos.

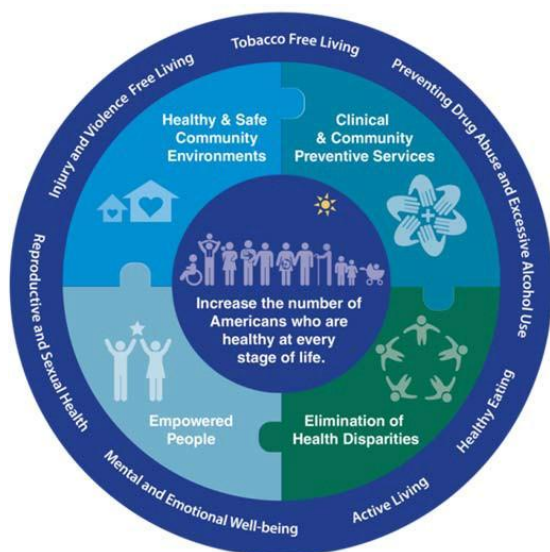
While our primary charge is to make recommendations to the Secretary and HHS, we strongly believe that it is time for all sectors beyond public health and medicine to embrace infant mortality as "their" issue and strategically maximize their investments. For example both the National Action Plan to Reduce Disparities and National Prevention Strategy contain infant mortality reduction activities. SACIM believes that actions are needed at the national, state, community, family, and individual levels, and through public-private partnerships to leverage innovation, technology, expertise, and community assets to achieve the goal of eliminating preventable infant deaths.

**SACIM recommends that HHS take the following actions to harness the public and private leadership, expertise and resources needed to reduce infant mortality,** prevent more adverse birth outcomes such as preterm birth, and help families achieve success in childbearing at the right time, right place, and with the supports they need.

#### **6.A. Engage the National Prevention Council and build upon the National Prevention Strategy.**

The National Prevention, Health Promotion, and Public Health Council (National Prevention Council), under the leadership of Surgeon General Regina Benjamin, MD, has a potential role to advance a cabinet-level, interagency focus on reducing infant mortality and closing the gap between African-American and white babies. Within HHS, many agencies and offices can make further contributions to infant mortality reduction efforts. These include but are not limited to: AHRQ, CDC, CMS, HRSA, NIH, Office of Adolescent Health (OAH), Office on Minority Health (OMH), Office of Population Affairs (OPA), Office on Women's Health (OWH), Office of the Surgeon General, SAMHSA and other parts of HHS. In addition, through the National Prevention Council HHS can also engage and partner with the Departments of Agriculture, Defense, Education, Labor, Homeland Security, Housing and Urban Development, Interior, Justice, Veterans Affairs, as well as the Corporation for National and Community Service, Domestic Policy Council, Environmental Protection Agency, Federal Trade Commission, Office of Management and Budget, and Office of National Drug Control Policy, and others carrying out the national strategy to reduce infant mortality.

**Figure 8. National Prevention Strategy**



**SACIM specifically recommends that HHS provide incentives for states and communities to implement approaches in the National Prevention Strategy for improving the health of women of childbearing age, men, and infants through community preventive services and public health approaches.** Under the priority topic “reproductive and sexual health” the National Prevention Strategy calls for specifically for increased attention to preconception, prenatal, and other reproductive health services. For example, it calls for HHS to promote and disseminate best practices and tools to reduce behavioral risk factors and to research and disseminate effective methods to prevent IPV. As illustrated above in Figure 8, other services and supports called for in the National Prevention Strategy — such as tobacco control, healthy eating, limited use of drugs and alcohol, active living, and safe home and community environments — are also critical to improved birth outcomes. More investment is needed to fulfill our nation’s prevention goals.



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“The strength and ingenuity of America’s people and communities have driven America’s success. A healthy and fit nation is vital to that strength and is the bedrock of the productivity, innovation, and entrepreneurship essential for our future. Healthy people can enjoy their lives, go to work, contribute to their communities, learn, and support their families and friends. A healthy nation is able to educate its people, create and sustain a thriving economy, defend itself, and remain prepared for emergencies.” *National Prevention Strategy*, page 6.

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#### **6.B. Strengthen state health departments with effective federal-state partnerships, particularly through activities underway at HRSA, CMS, and CDC.**

States are the engine of innovation and the drivers of health policy change in the United States. This has long been true. The recent Healthy Babies Initiative of the Association of State and Territorial Health Officials (ASTHO) and the compendium of ideas on improving birth outcomes and reducing infant mortality<sup>152</sup> prepared by the Association of Maternal and Child Health Programs (AMCHP) are just two examples.

Several recent initiatives of HRSA, CMS, and CDC (many mentioned above) are mechanisms to strengthen federal-state partnerships in reducing infant mortality. In particular, we note the importance of the HRSA Collaborative Innovation and Improvement Networks (COIN), the potential to use Strong Start to demonstrate care models beyond prenatal care (e.g., preconception care, regional perinatal care), and the potential for CDC to support better surveillance and data systems.

#### **6.C. Maximize the potential of public-private partnerships, particularly by engaging private sector organizations which have a distinct focus on preventing infant mortality.**

The list of potential partners is long; however, SACIM notes the particular contributions in recent years of the March of Dimes, AMCHP, and ASTHO. In addition, SACIM acknowledges the important role of professional organizations such as the American College of Obstetricians and Gynecologists (ACOG), American Academy of Family Physicians (AAFP), American College of Nurse Midwives (ACNM), American Public Health Association, Association of Women’s Health, Obstetric, and Neonatal Nurses (AWHONN), Society for Maternal Fetal Medicine, and others.

**6.D. Engage women (daughters, mothers, and grandmothers) in efforts to prevent infant mortality, improve women’s health, and strengthen family health and well-being.**

With the creation of the White House Council on Women and Girls in October 2009, President Obama signaled his recognition that the issues facing women are not just women’s issues. The Council’s purpose is to ensure that each federal agency takes into account the needs of women and girls in federal policies and programs. SACIM strongly believes that engaging and empowering women will be essential to reducing U.S. infant mortality rates and having stronger, healthier men, women, children, and families.

## **APPENDIX A: Continuum of Services to Prior to Birth Improve the Health of Women and Birth Outcomes**

## ***Preconception***

## ***Prenatal***

## ***Birth***

## ***Interconception***

Care consistent with Reproductive Life Plan

Family planning

Immunization

Folic acid

No exposure to teratogens

Alcohol management

Alcohol cessation

Screening & treatment for STI, HIV, and other infections

Healthy weight

Smoking cessation

Maternal chronic disease control

Psycho-social supports and services

Education and support for breastfeeding

Screening & treatment for behavioral / mental health

Evidence-based home visiting

Prenatal & interconception intensive, multidisciplinary care coordination for high risk

Early, continuous, & quality prenatal care

Identification of signs of preterm labor

Effective use of 17P

No elective preterm delivery

Postpartum Visit

Birth in quality, risk appropriate facility

Interconception care consistent with reproductive history

***Better health for women***

***Reduced fetal mortality***

***Improved birthweight distribution***

***Reduced preterm birth***

***Reduced birth defects***

***Reduced infant mortality***

***Better infant & child health outcomes***

***Reduced infant & child morbidity***

## **APPENDIX B: Continuum of Services Following Birth to Improve Infant Health and Survival**

## ***Birth***

## ***Newborn/neonatal***

## ***Postneonatal***

Birth in quality,  
risk appropriate  
facility

NICU  
quality &  
safety

Well-child care based on Bright Futures

Immunization

Diagnostic & treatment services

Education on child development and parenting

Injury & SIDS prevention

Protection from violence, home and community safety

Quality early care and education

Newborn screening  
with appropriate follow up

Intergenerational screening  
& treatment for mental health

Education and support for breastfeeding

Smoking cessation yielding smoke free environment for infant

Evidence-based home visiting

***Better health  
for women***

Women's Clinical  
Preventive Services

Family Planning &  
Reproductive Life Plan

Well-woman visits &  
Pre/interconception Care

***Reduced infant mortality***

***Improved survival for  
low birthweight &  
preterm infants***

***Reduced infant  
& child morbidity***

***Optimized health &  
developmental outcomes***

***Better infant  
& child health  
outcomes***

## APPENDIX C: Opportunities to Improve Infant Mortality through Implementation of the ACA

SACIM members believe that the following opportunities to fine tune implementation of the ACA are particularly important for reducing infant mortality and improving the health of women, infants, and families.

### *Coverage, Benefits, and Patient Protections*

- **Inform women of their coverage options, rights, and opportunities to gain access to health coverage and care.** This would include promotion of the women's clinical preventive services package. The Office of Women's Health has created one grant opportunity. This work should be continued and expanded.
- **Inform families about the preventive services coverage for Bright Futures well-baby care, immunizations, and newborn screening.** Continued emphasis on well-baby visits, immunizations, and newborn screening can save lives as those factors that lead to death during the post-neonatal period are well-known and amenable to intervention.
- **Promote utilization of benefits among newly covered young adults to age 26.** Pregnancy and birth rates are highest for women in their twenties, particularly ages 20-24. Promoting the use of preventive and other health care is especially important for this age group. (We should not wait until they are pregnant.)
- **Protect CHIP and Medicaid coverage for children.** The ACA's "maintenance of effort" provision requires that States maintain eligibility for children enrolled in the Medicaid program in families earning <133% of the federal poverty level or the CHIP program until 2019. These provisions, plus automatic newborn eligibility and continuous eligibility through the first year of life under Medicaid, are vital to low-income infants.
- **Monitor pre-existing condition exclusions for children.** Infants are protected by the ACA provision that prohibits health plans from denying insurance to children due to pre-existing conditions. Birth defects and other congenital conditions were formerly considered pre-existing conditions by some plans. HHS should monitor compliance.

### *Innovation and Focus through Medicaid*

- **Use the Center for Medicare and Medicaid Innovations to demonstrate the effectiveness of new care models.** The *Strong Start* grant opportunity to evaluate the effect of enhanced prenatal care is an important step. Future innovations grants – maybe another stage of *Strong Start* – could demonstrate approaches that span the continuum from family planning through pregnancy and birth to 24 months of interconception care for



low-income, high-risk women and infants. Innovation Grant Challenge projects also should include efforts aimed at improved quality in newborn and regional perinatal care.

- **Support States' use of Medicaid health homes for women of childbearing age with chronic conditions.** For women of childbearing age, for example, such projects might aim to provide an effective, patient-centered medical home for women with two or more chronic conditions (e.g., asthma, obesity, diabetes, substance use disorder, mental health conditions). Each of these conditions increases risk for an adverse birth outcome.
- **Encourage and permit states to demonstrate the effectiveness of interconception/interpregnancy care in Medicaid.** In 2011, Georgia implemented the first Medicaid waiver to focus on interconception care building on a successful Atlanta project. Louisiana has CMS approval for a similar project in New Orleans. Other states are seeking State Plan Amendments and CMS approval for projects that should not require waivers. Demonstration projects now can help to inform action when Medicaid coverage is expanded under ACA in 2014.

### *Home Visiting*

- **Enhance the role of home visiting programs in supporting interconception health.** Current home visiting models for mothers and young children have not led to consistent and significant improvements in maternal health outcome. This stands in contrast to their results for children. *Strong Start* will link to the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program evaluation (particularly in relationship to birth outcomes); however, we call for more attention to prevention of adverse outcomes in subsequent pregnancies through interconception care for mothers served in the MIECHV program.

### *Primary Care Capacity and Workforce Development*

- **Maintain the ACA multi-billion dollar commitment to expansion of community health centers** (CHCs, also known as federally qualified health centers—FQHCs—under the Medicare and Medicaid programs). CHC/FQHCs are experts in delivering care in a patient-centered medical home, with teams of providers and address both the medical and social determinants of health. The comprehensive primary care delivered by CHC/FQHCs can help to reduce racial/ethnic and income disparities in infant mortality.
- **Maximize opportunities in the ACA to improve the primary care and public health workforce.** These include investments in training for primary care physicians, nurses, the public health workforce, and community health workers. Such investments will generate the workforce needed to care for women, infants, and families.

## *Prevention and Public Health*

- **Promote breastfeeding.** HHS should collaborate with the Department of Labor to monitor and protect breastfeeding mothers' right to reasonable break time and appropriate space in the workplace to express breast milk as enacted through the ACA. Also monitor state Medicaid financing for breastfeeding.
- **Protect the Prevention and Public Health Fund.** Twice, the Prevention and Public Health Investment Fund dollars have been used to fund other priorities. These funds are vitally needed to focus on the health and wellness of our families and communities.
- **Encourage states to use Community Transformation Grants (CTGs) to address the chronic disease risks and needs of women of childbearing age.** Without specific direction related maternal and child health, many grantees have not partnered or focused on women of reproductive age and/or children. More explicit guidance is needed.
- **Guide states and communities toward approaches for improving the health of women and infants through the National Prevention Strategy.** The Strategy calls for increased preconception, prenatal, and other reproductive health services. The tobacco control, healthy eating, limited use of drugs and alcohol, active living, and safe home and community environments called for in the Strategy also are critical to healthy babies.

## **APPENDIX D. Crosswalk between HHS Action Plan to Reduce Racial and Ethnic Health Disparities and SACIM recommendations to reduce infant mortality**

The HHS Action Plan to Reduce Racial and Ethnic Health Disparities and its companion document the National Stakeholder Strategy for Achieving Health Equity, a product of the National Partnership for Action (“NPA Stakeholder Strategy”), define clear approaches and actions. Many of the identified strategies and actions align with SACIM recommendations.

The HHS Disparities Action Plan proposes a set of Secretarial priorities and five strategic goals from the HHS Strategic Plan for Fiscal Years (FY) 2010-2015 provide the framework for the HHS Disparities Action Plan. (page 11) They are to:

- I. Transform health care;
- II. Strengthen the nation’s Health and Human Services infrastructure and workforce;
- III. Advance the health, safety, and well-being of the American people;
- IV. Advance scientific knowledge and innovation; and
- V. Increase the efficiency, transparency, and accountability of HHS programs.

SACIM has proposed to six areas for the national strategy to reduce infant mortality that overlap with the Disparities Action Plan goals.

- 1. Improve the health of women prior to pregnancy.**
  - a. As called for by the HHS Disparities Action Plan (I.A), SACIM recommends increasing insurance and access to preventive services, particularly for low-income, minority women who are uninsured.
- 2. Ensure access to safe and high-quality, patient-centered care**
  - a. Example 1: SACIM recommends building upon the COIN strategy launched in 13 Southern states to capitalize on the partnership of MCHB/HRSA, CMS, ASTHO, NGA, and MOD. These states have some of the greatest racial and ethnic disparities in birth outcomes.
  - b. Example 2. As called for by the HHS Disparities Action Plan (I.B), SACIM recommends expanding community health centers and National Health Service core in medically underserved areas and using community-based health teams to support and enhance primary care effectiveness.
- 3. Redeploy key evidence-based, highly effective preventive interventions to a new generation of parents.**
  - a. Example 1: SACIM has recommended giving high priority to topics such as immunization, breastfeeding, smoking cessation, and family planning where rates of utilization have stagnated.

- b. Example 2: As called for by the HHS Disparities Action Plan (III.A.2), SACIM recommends education campaigns regarding preventive benefits.
- 4. **Increase health equity and reduce disparities by targeting social determinants of health through both multi-sector investments in high-risk, under-resourced communities and major initiatives to address poverty.**
  - a. Example 1: As called for by the HHS Disparities Action Plan (II.B), SACIM calls for increased use of community health workers, promotoras, and doulas to provide education, navigation, and support to individuals in their communities.
  - b. Example 2: Use interagency collaboration to turn the curve on social determinants of health at the community level by connecting and concentrating federal resources of Healthy Start, community health centers, home visiting, housing, education, child care, transportation, and other federal resources (these might be known as Best Baby Zones).
  - c. Example 3: As called for by the HHS Disparities Action Plan (III.A.5), SACIM also recommends continued emphasis on programs such as the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program that aim to address multiple risks and protective factors that affect more vulnerable families.
  - d. Example 4: As is called for in the HHS Disparities Action Plan (II.C.2), SACIM members have called upon the Secretary to use reauthorization of TANF as an opportunity to increase education and training in communities with high levels of infant mortality.
- 5. **Invest in adequate data, monitoring, and surveillance systems to measure access, quality, and outcomes**
  - a. Example 1: As is called for in the HHS Disparities Action Plan (3.a page 13), SACIM recommends that CMS to implement measures and incentives to improve health care quality for women and infants.
  - b. Example 2: Support standardized vital statistics and incentivize linkage among vital statistics, Medicaid, and other health data to boost transparency and accountability.
- 6. **Maximize the potential of interagency, public-private, and multi-disciplinary collaboration.**
  - a. Example 1: As recommended in the HHS Disparities Action Plan (IV.B), SACIM members have called for research to inform disparities reduction, including new analyses of the factors that drive disparities in outcomes today, more community-based participatory research, and testing innovative strategies.

## APPENDIX E. Specific HHS Action to Increase Breastfeeding

HHS could expand promotion of and support for early, exclusive and continued breastfeeding by:

- Continuing the work of the *HHS Working Group for Worksite Lactation Support*, a partnership between the Office on Women's Health and HRSA
- Continuing the National Breastfeeding Helpline as part of the National Women's Health Information Center (OWH)
- Supporting education related to breastfeeding in undergraduate and graduate medical and nursing school curriculum as part of the federal support for medical and other health professional education
- Sponsoring research on how best to support breastfeeding success, especially among most vulnerable populations (NICHD)
- expanding funding for federal- and state-level breastfeeding initiatives that support community actions, such as breastfeeding support in child care settings, among faith-based organizations, and in K-12 education
- Sponsoring a report on current state initiatives (HRSA, CDC)
- Support the development of additional Donor Milk Banks to achieve the Joint Commission goal (CDC, HRSA-MCHB)
- Complementing WIC breastfeeding support with social marketing campaigns using PSAs and social media (OWH, USDA)
- Including breastfeeding education and support in all related obesity and diabetes prevention projects (CDC, HRSA-MCHB)
- Issuing additional guidance on the ACA provisions related to breastfeeding support (DOL, OWH)

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## ADVISORY COMMITTEE ON INFANT MORTALITY (ACIM 2013)

### ADVISORY COMMITTEE MEMBERS

**Mark Bartel, M. Div, BCC**  
Manager, Spiritual Care  
Arnold Palmer Medical Center  
Orlando, Florida

**Sharon M. Chesna, M.P.A.**  
Executive Director  
Mothers & Babies Perinatal Network  
of South Central New York, Inc.  
Binghamton, New York

**Robert Mande Corwin, M.D., FAAP**  
Elmwood Pediatric Group  
Clinical Professor of Pediatrics  
University of Rochester School of Medicine  
& Dentistry  
Clinical Professor Emeritus  
State University of New York Upstate  
Medical University

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Medical Affairs  
Providence Hospital  
Washington, D.C.

**Phyllis Armelle Dennery, M.D.**  
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University of Pennsylvania School of Medicine  
Werner and Gertrude Henle Chair and Chief  
Division of Neonatology  
Children's Hospital of Philadelphia  
Philadelphia, Pennsylvania

**Carolyn L. Geger, C.N.M., M.S., F.A.C.N.M.**  
Program Director and Assistant Professor  
Nurse-Midwifery Program  
School of Nursing and Health Studies  
Georgetown University  
Washington, D.C.

**Arden Handler, Dr. P.H., M.P.H.**  
Professor of Community Health Sciences,  
Maternal and Child Health  
University of Illinois at Chicago  
School of Public Health  
Chicago, Illinois

**Fleda Mask Jackson, Ph.D., M.S.**  
Senior Scientist  
Emory University  
Rollins School of Public Health  
Atlanta Regional Health Forum  
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Director, Carolina Global Breastfeeding Institute (CBI)  
Department of Maternal and Child Health  
The Gillings School of Public Health, CB#7445  
The University of North Carolina at Chapel Hill  
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Past President, Parents of Infants and Children  
with Kernicterus (PICK)  
Washington, D.C.

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College of Public Health  
Tampa, Florida

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Centers for Medicare and Medicaid Services  
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Health Resources and Services Administration  
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Agency for Healthcare Research and Quality  
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Food and Nutrition Service  
U.S. Department of Agriculture  
Alexandria, Virginia

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Employee Benefit Security Administration  
U.S Department of Labor  
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